INFORMATION NEEDS OF COLORECTAL CANCER PATIENTS AND SOCIOTECHNICAL FACTORS AFFECTING THE USE OF PATIENT PORTALS IN OUTPATIENT CHEMOTHERAPY

by

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Abstract

Patient engagement, especially with the use of patient portals, is expected to play an important role in improving healthcare quality and cost reduction. This study aimed at gaining an understanding of the information needs of colorectal cancer (CRC) patients, current healthcare professional (HCP) workflows, and assessing how the needs of both parties may be met in the current Health IT (HIT) environment within the outpatient chemotherapy setting. A qualitative cross-sectional study using semi-structured in-depth interviews was conducted with CRC patients undergoing outpatient chemotherapy and HCPs who provided care to this patient population. Interview transcripts were analyzed using a directed approach content analysis. Systems Engineering Initiative for Patient Safety (SEIPS) model provided the foundation for the research model and hence the initial coding categories. A majority of the patients used the patient portal (MyChart) to fulfill their information needs of self-managing test results and appointments, but not so much to coordinate care or to communicate with their HCPs. Sociotechnical barriers to patient and HCP use of the patient portal were identified and action agenda to counter such barriers were proposed. This study contributed to the literature of effective patient portal implementation as well as the emerging field of *Patient-Engaged Human Factors and Ergonomics* (HFE) by applying a holistic human factors approach to identifying potential root cause of implementation barriers and generating an actionable agenda.

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1. Introduction

Patient engagement is a relatively new concept that is expected to play an important role in improving healthcare quality and cost reduction by patients taking an active role in his or her own disease management.[1,2] Since offering patients the means to easily access, manage, and use pertinent health information is a crucial step in enabling patient engagement,[3,4] technologies such as patient portals and tethered Personal Health Records (PHR) that allow patients to access part of their medical records and services to coordinate care at the convenience of their homes have garnered significant attention. The heightened interest in using patient portals by healthcare organizations is also stimulated by Federal initiatives such as the Centers for Medicare and Medicaid Services (CMS) Electronic Health Record (EHR) Incentive Program – also called Meaningful Use (MU) – which provides financial incentives to Eligible Hospitals (EH) and Eligible Professionals (EP) for their "meaningful use" of patient portals.[5,6] Specifically, MU Stage 2 requires that: (1) 50% of patients can access their health information (e.g. test results) online within 4 business days after the information is available to the EP; (2) 5% of patients use secure electronic messaging function of the patient portal; (3) After Visit Summaries (AVS) are provided to patients within 1 business day for more than 50% of office visits; and (4) 10% of patients are provided with education materials.[7] To receive the most incentive payments, EPs and EHs need to satisfy Stage 2 criteria after their first two years of attesting to Stage 1.

While some studies have demonstrated the potential benefits of patient portals – such as improved clinical outcomes, patient satisfaction, provider productivity, and patient-

provider relationship [8–11] – others show otherwise.[12–14] These equivocal findings point to the fact that effective implementation of a patient portal requires an understanding of the unique information needs and information management strategies used by the patient population of interest, and how the new tool can fit their current workflow to meet such needs.[15–18] Given the collaborative nature of patient portals, a holistic approach that directly compares the perspectives of patient and Health Care Professional (HCP) preferences (e.g. preferred information source and communication mode for certain information need) is also important in understanding what the role of patient portal should be in their current care settings.[19–23]

One of the patient populations who would especially benefit from an effective implementation of patient portal is cancer patients receiving chemotherapy treatment, where economic and policy changes have shifted chemotherapy administration from inpatient to outpatient[24] resulting in significant increase in the responsibility of patients and their caregivers in managing their disease and side effects at home. Offering access to their health information in a timely manner through patient portals also seem essential for these patients given the strong relationship between information provisioning and cancer patients' health-related quality of life, anxiety, depression, self-efficacy, locus of control, and symptom distress.[25–28]

While information-seeking and management are recognized as important methods for patients to cope the emotional burdens of cancer diagnosis and treatment,[29–31] it is also known that information needs and information management strategies of cancer patients

vary greatly depending on the type of cancer and the stage of treatment (e.g. pre-surgery, post-surgery, chemotherapy, radiation, post-treatment (survivorship)). However, most studies on patient portal use by cancer patients do not differentiate diagnosis.[25,32,33] Furthermore, little is known about the information needs of patients with colorectal cancer (CRC), despite it being the third most commonly diagnosed cancer in men and women and the second leading cause of cancer deaths.[25,34,35] Less than 40% of cases are diagnosed at a local stage, which leads to the need for approximately 70% and 85% of patients to receive chemotherapy as part of their treatments for later stage colon and rectal cancers, respectively.[36] Outpatient administration of fluorourasil (5-FU)-based chemotherapy regimen usually used in the treatment of CRC involves frequent clinic visits and management of treatment-related side effects at home over the course of 6 months or more.[37,38]

To fully realize the potential benefits of patient portals in supporting CRC patients during their chemotherapy treatment, one must first understand their information needs and management strategies used at home. Simultaneously, investigation of current HCP workflow and preferences are essential in optimizing the implementation of patient portals in their current care setting. *The purpose of this study was precisely to gain an understanding of these information needs and to assess how they might be met in the current Health IT (HIT) environment.*

2. Background

In June 2013, the Outpatient Oncology Department of the Sidney Kimmel Comprehensive Cancer Center (SKCCC) at Johns Hopkins Hospital went live with MyChart, a web-based patient portal affiliated with The Epic Enterprise EHR. The web-based portal offers the following features for patients[39]:

- View-only access to portions of medical record including test results (labs, radiology, and pathology), diagnoses, medications, and immunizations
- View AVS and post-appointment instructions
- Submit requests to update medication and allergy lists
- Secure messaging with health care team
- Request appointments and view past and upcoming appointments
- Request prescriptions refills
- Access information from the Johns Hopkins Medicine record for patient's child under age 18 or for other family members (proxy authorization required)

MyChart is intended to support patients with three types of processes that require active engagement of patients and/or their non-professional caregivers (hereafter referred to as 'Patient-Engaged Processes'): 1) Self-management of Personal Health Information (PHI) and appointments (e.g. tracking test results and upcoming appointments), 2) Care coordination (e.g. requesting appointments and prescription refills), and 3) Communication with HCPs (e.g. asking non-urgent medical questions via secure messaging) **(Table 1)**.

Currently, MyChart is a generic patient portal that is not customized per specialty. This is problematic in two ways. First, the system is not specifically designed to address the information needs or the management strategies used by oncology patients with different types of cancer or at different stages of treatment. Second, the implementation process does not take into account the current clinical workflow or patient engagement efforts already practiced at SKCCC, which could compete with the functions of MyChart. Not addressing such problems may hinder patient adoption of MyChart, which in itself is a lost opportunity for patient-provider partnership, but further jeopardizes organizational revenue by not meeting the incentive criteria.

3. Research Question

This qualitative cross-sectional study was designed to (1) explore the information needs of CRC patients in their disease management while undergoing chemotherapy treatment, (2) investigate what and how sociotechnical factors affect the way CRC patients and HCPs currently collaborate in managing their outpatient chemotherapy treatment and its side effects outside the clinic, and (3) develop an action agenda informing the users on the optimal use of MyChart that will facilitate this collaboration. To accomplish the above study objectives, following specific research questions guided the data collection and analysis:

Specific Research Question 1 (CRC patients): What are the CRC patients' chemotherapy-related information needs, their treatment and side effects management processes at home, and their preferences for patient-HCP communication methods outside clinic?

Specific Research Question 2 (HCPs): What are the HCPs' perceptions of CRC patients' chemotherapy-related information needs, collaborative management processes, and preferences for patient-HCP and HCP-HCP communication methods?

4. Methods

4.1 Sociotechnical Systems Framework: SEIPS model

To capture the multifaceted interactions among various sociotechnical factors and how they shape the works performed by patients and HCPs, the Systems Engineering Initiative for Patient Safety (SEIPS) model provided the foundation for the research model **(Figure 1)**. Sociotechnical work system consists of five components where "a *person* performs a range of *tasks* using various *tools and technologies*…The performance of these tasks occurs within a certain *physical environment* and under specific *organizational conditions*", which produce work processes and in turn shapes the outcome.[40] Although the model was originally developed exclusively to study HCPs' clinical works and to improve patient safety, the authors recently extended the model into 'SEIPS 2.0' to incorporate the concept of *engagement*, which recognizes the various health-related "work" performed by patients[41] and HCPs separately and collaboratively.[42] Since the Patient-Engaged Processes supported by MyChart are essential part of 'Patient Work' and 'Collaborative Work' discussed in SEIPS 2.0, the model was believed to offer a solid foundation for this study. In fact, human factors and ergonomics (HFE) researchers have recently begun to apply HFE principles and methods in what they call an emerging area of "patient-engaged HFE" to study the works performed by patients outside clinical settings that ultimately impact the outcome of patient-provider collaborative work.[43] This study aims to contribute to this field of patient-engaged HFE by applying the SEIPS model to understand the work performed by CRC patients at home and to explore how MyChart could assist their work.

4.2 Interview Guide Development

The original SEIPS model and the notion of *engagement* proposed in SEIPS 2.0 guided the development of the initial interview guides **(Appendix 1)**. For example, interview questions for patients included patients' information needs that arise at home (*person*; *task*), preferred information sources and communication methods (*tools and technologies*; *task*), who or what has been helpful in managing their care (*organization* – e.g. family members; *tools and technologies*) and previous experience (or lack of) with MyChart (*tools and technologies*). As noted earlier, MyChart is intended to support three Patient-Engaged Processes: Self-Management, Care Coordination, and Communication. To map their current information needs and management strategies used to the optimal MyChart-enabled processes, the interview guide questions focused on eliciting the work system components that are mainly pertinent to the three processes. Moreover, since the research objective was primarily focused on processes that require *informational* tasks (e.g. calling the triage nurse with symptom management questions; searching and tracking novel treatment options), which are rarely affected by the *physical environment* (e.g. lighting, noise, clutter, etc.), questions regarding *physical environment* (*internal environment* in SEIPS 2.0) were not explicitly included in the interview guide. However, probes related to difficulty or barrier to accomplishing *tasks* elicited a few responses regarding *physical environment*. Also, SEIPS 2.0 has a sixth component (*external environment*) to incorporate the "macro-level societal, economic, ecological and policy factors outside an organization"[42] (e.g. MU Incentive Program) but since governmental-level factors are out of scope of this study, the component was omitted from the interview guide. To establish validity, three domain experts reviewed the initial interview guides: one of the authors of

the SEIPS model, an oncology nurse educator, and an oncologist specializing in CRC patient care **(Acknowledgements)**. Revisions were made iteratively to the interview guides as needed from analysis of early transcripts **(Appendix 2)**.

4.3 Study Design and Setting

A qualitative cross-sectional study using semi-structured in-depth interviews was conducted with CRC patients with later stages of the disease, who were actively being treated with chemotherapy and HCPs who provided care to this patient population. The study was conducted at the Sidney Kimmel Comprehensive Cancer Center (SKCCC)'s outpatient chemotherapy infusion center located in the Johns Hopkins Hospital East Baltimore Medical Campus. The study was conducted from February 2014 to May 2014 after approval of the Johns Hopkins Medicine Institutional Review Board.

4.4 Sampling and Recruitment

To enable a direct comparison of patient and provider perspectives, a stratified purposeful sampling[44] was employed to recruit two subgroup participants: (1) CRC patients who were actively receiving outpatient chemotherapy treatment at SKCCC at the time of the interview for either Stage 3 or 4 (metastatic) CRC (the study did not exclude patients who were simultaneously receiving other treatments e.g. radiation therapy), who were over the age of 18, English speaking, and without hearing or communication-impairment and (2) HCPs who were English speaking GI Attendings, Fellows, and oncology nurses, who provide care to the above-mentioned CRC patients. The HCP did not have to be in the care provider role for the recruited patients at the time of the interview to be eligible. Due

to the qualitative nature of the study, final sample size was decided at the end of data collection and analysis process based on the idea of "conceptual saturation".[45]

Patient participants were recruited with the assistance of oncology nurses working in the infusion center. Oncology nurses handed recruitment fliers to their CRC patients during their chemotherapy treatments **(Appendix 3)**. Patients interested in participating informed their oncology nurses, who then notified the study investigator. The study investigator approached the patients in person and, if they felt comfortable going forward with the interview, performed the consent process and interview while they received treatment inside the infusion center. The study investigator directly recruited HCP participants by word of mouth and by e-mail **(Appendix 4)**. When interested HCPs responded, a date, time, and location for interviews were agreed upon.

4.5 Data Collection and Management

Before beginning the interview, participants were handed a copy of the oral consent script **(Appendix 5)** and asked to read through as the study investigator read the script explaining the purpose of the study, the duration (15 – 20 minutes), and the need to audio-record the interview but that no identifiable data will be collected for the purpose of the study. All participants were ensured that their participation is voluntary, that he or she can request erasure of any or all parts of a digital voice record during and just after data collection, and that the study will not affect their care or employment in any way.

Semi-structured in-depth interviews using the aforementioned interview guides were conducted with participants who gave consent. All interviews were audio-recorded using the SONY® Digital Flash Voice Recorder ICD-PX312 and transcribed verbatim. Patient participants' basic demographic data on age, sex, race, and MyChart sign-up status were collected at the beginning of each interview. Interview questions for patients focused on patients' information needs that arise at home, current self-management and care coordination strategies used, preferred communication methods with HCPs, and previous experience (or lack of) with MyChart. Interview questions for HCPs focused on their perceptions of patients' information needs, perceptions of and preferences on the current patient-HCP and HCP-HCP communication processes (which includes the MyChart/Epic communication functions) used for symptom management and care coordination with patients at home.

To protect confidentiality, all subjects were given a unique identifier (UI). All data files (e.g. interview recordings and transcripts) were labeled following a strict file naming convention using the UI **(Appendix 6)**. Patient demographic information and HCP roles were recorded on a data spreadsheet with their given UI and stored on a password-protected hard drive (WD My Passport for Mac 1TB WDBLUZ0010BSL-NESN) kept in the locked office of the study investigator. All audio recordings were deleted from the digital voice recorder immediately once they were stored as MP3 files and saved on the said local password-protected hard-drive. All MP3 files were deleted from the hard-drive once transcribed. Transcripts from the interviews were redacted to remove any identifiable information prior to analysis.

4.6 Data Analysis

Transcripts of the interviews were imported into NVivo 10 for Mac Beta for content analysis using a directed approach (or at times referred to as deductive category application).[46,47] In a directed content analysis, the researcher uses key concepts or variables from an existing framework as initial coding categories, which is followed by iterative category/sub-category development. First, interview passages were extracted if they mentioned any patient information needs, self-management and care coordination strategies (including patient-HCP and HCP-HCP communication processes), and experiences with or perceptions of MyChart. Next, the passages were coded separately for patient transcripts and HCP transcripts using the five sociotechnical work system components – *person*, *organization*, *task*, *tools and technology*, and *physical environment* – as initial coding categories, where each component's attributes or characteristics outlined in SEIPS 2.0 model[42] guided the operational definitions of the categories **(Table 2)**. Codes were applied at the level of sentences that constituted a *meaning unit*, that is, "the constellation of words or statements that relate to the same central meaning… through their content and context".[48] Passages under each category were then – again separately for patients and HCPs – further coded into sub-categories. Passages were also coded with *Process* categories to understand the current workflows related to the three Patient-Engaged Processes.

Based on the notion that the frequency of codes represent topics that are common or important to the participants,[49] the relative number of all codes representing patient information needs were graphed for between-group comparisons to explore the degree of

alignment between actual patient information needs and HCP-perceived patient information needs. Similar analysis was repeated for codes representing patient- and HCP-perceived facilitators and barriers to MyChart use.

5. Results

5.1 Participant Demographic and Clinical Characteristics

A total of 20 participants (10 patients and 10 HCPs) were interviewed. For both groups, 70% of the interviewees were female and 80% were white. Patient participants ranged in age from 41 to 84 years old (mean = 58.2). Seven patients had MyChart accounts that were being actively used, of which 2 accounts were accessed and managed solely by their family members logging in as the patient. Two of the three patients who had not yet signed up for MyChart showed interest in using the portal. Majority of the patients – except one patient who lived alone with her young child – had at least one family member either living together or visiting frequently and supporting the patient with various tasks at home. Most of the patients reported that they lived with their spouses, five of whom were physically present during the interviews. The reported time since the first diagnosis ranged from 2 months to 7 years (mean = 3 years). All patients who specifically commented on their current chemotherapy regimen (n = 8) had first been on FOLFOX then moved on to their current regimens. Early interviews with the oncology nurses revealed the important role of triage phone nurses (hereafter referred to as 'triage nurses') in answering patients' questions and concerns that arise at their homes, such as symptom management. Hence, HCP participants included 3 triage nurses, 5 oncology

nurses, and 2 physicians. **Table 3** summarizes the demographic and clinical characteristics of the participants.

5.2 Qualitative Data Characteristics

Table 4 summarizes the characteristics of qualitative data collected and analyzed for this study. Patient interviews ranged from 10 min 17 sec to 34 min 14 sec (mean = 23 min 13 sec) while HCP interviews ranged from 10 min 7 sec to 32 min 53 sec (mean = 19 min 11 sec). A total of 10 patient interview transcripts yielded 286 meaning units coded with Process categories, which were further broken down into work system components that ultimately resulted in a total of 901 unique meaning units. Similarly, 10 HCP transcripts yielded 300 meaning units coded with *Process* categories, which resulted in a total of 615 unique meaning units categorized into work system components. A complete list of all codes, the number of transcripts containing each code, and all code frequencies for patient and HCP transcripts could be found in **Appendices 7 and 8**, respectively. HCP transcripts were coded first while simultaneously updating its codebook **(Appendix 9)**. As the researcher became more familiar with the coding software, it became apparent that having self-explanatory code names – rather than creating a separate codebook – better served the data analysis process. Hence, patient transcripts did not have a separate codebook.

5.3 Information Needs of CRC Patients: Actual vs. HCP-perceived

Table 5 and 6 lists information needs described by CRC patients and by HCPs as their perception of patients' information needs, respectively. As depicted in **Figure 2**, a majority of the respondents from both groups frequently discussed information needs related to test results (including lab and imaging tests) and side effects. Most respondents also mentioned information needs related to appointments and medications but with less frequency. More than half of the patients discussed their initial need for information on home care procedures (i.e. how to manage infusion pumps, ports, and/or ostomy bags), while none of the HCPs did. Similarly, higher number of patients discussed their need to know about the plan of their care beyond their current treatment and potential treatments alternative to chemotherapy, while HCPs' perceptions mainly focused on aspects of their current care.

The above results show that MyChart is indeed equipped with the functions capable of fulfilling the majority of patient information needs. While patients seem to utilize the self-management features of MyChart, however, further analysis revealed that most patients do not consider using MyChart in care coordination or as a communication tool with HCPs **(Table 7)**. Furthermore, since HCPs seem to recognize what the patient information needs are – and most likely have the basic knowledge about MyChart and its capabilities through Epic training – factors other than misunderstandings about patient needs and MyChart seem to play an important role in whether or not the HCP recommends the use of MyChart to his or her patient.

The following sections will describe how different sociotechnical factors affect the way patients and HCPs currently collaborate in managing their outpatient chemotherapy treatments and their preferences for using MyChart in patient-engaged processes.

5.4 Sociotechnical Factors Affecting Patient-Engaged Processes

5.4.1 Self-Management of PHI and Appointments

As depicted in **Figure 5**, every chemotherapy appointment is preceded by a lab test to check whether the patient is in good condition to receive the treatment. Patients could either come in for a lab test on the day of their treatment and receive a printed copy of the lab result from their nurse, who will also let them know if the result was ok for treatment, or visit an outside lab the day before and call the triage line to check whether to come in the next day or not. Due to the timing of test result release to patients via Epic **(Figure 6)**, patients can only access their lab results after their chemotherapy appointment. Despite the time lag, many patient participants and their family members who use MyChart mentioned their satisfaction with MyChart in meeting their needs to keep track of results, especially the CEA value:

> I do get [printed copy] from [the Nurse], but sometimes like the CEA number, which is the one I'm most interested in, it doesn't come through in time so…that's funny, that one is later than the others so I actually end up looking on MyChart, REALLY, for those results… (Female patient)

Patients were also satisfied with the ability to keep track of upcoming appointments in MyChart, especially in the case of leaving the clinic without receiving the print out about next appointment **(Figure 7)**.

Table 7a summarizes the facilitating factors in using MyChart for self-management of PHI and appointments. The success of MyChart in this process stems from the following facts: (1) MyChart's functions (*Tools/Technology* column, also detailed in **Table 8a**) help fulfill patient information needs (*Patient* and *Task* columns, also detailed in **Table 5**) without additional burden by simply supplementing the conventional methods already familiar to both patients and HCPs (e.g. handing out printouts), and (2) the advice HCPs give to patients about self-management (*Organization* column, stemming from **Table 9a** and **Table 10** "HCP Facilitator") align well with patient information needs.

Despite the concern of HCPs that accessing data alone might increase anxiety or put extra responsibility on an already overwhelmed patient **(Table 9b)**, patients learn to strategize various coping methods, such as having family members be in charge of information management (*Organization*), or to only access certain data:

> [I] trashed the email without reading the [attached] scan because I don't NEED to know the gory detail… I just made a command decision I didn't WANT to know how bad it was… I'm looking forward to the NEXT scan and how much BETTER it got {small laugh} (Male patient).

A female participant described how she had stopped reading the scan reports (she continues to look at her blood test results) over the years, but still appreciates having access and being able to share the information with others. This pattern seemed true for most of the patient participants with greater than three years since diagnosis:

> I know what's too scary for me at this point and…you know in the beginning before I had a lot of surgeries I did want to see all of my scan reports…once I started to have a lot of post operative changes and ablations and things like that…they were adding other paragraphs of stuff that I don't know what it meant…then we would go, "do I have a new disease or not". And so I don't really look at the scans, but for me it's useful to be able to go in and if the report hasn't been made available [between institutions] I can print it for my team.

5.4.2 Care Coordination

Table 7b summarizes patient preferences (which, in turn, are barriers to using MyChart) in care coordination. In a routine chemotherapy visit, patients usually leave the clinic with the next appointment scheduled, and no further action by the patient is required **(Figure 7)**. When appointments need to be changed, however, patients would have to first get a hold of their HCPs and figure out their availabilities (i.e. Communication with HCPs) before requesting the change. Conventionally, patients would call the Schedulers, who would communicate with the HCPs on behalf of the patients, coordinate schedules, and call back the patients with their new appointments. It is no surprise, then, that the patients, who are physically and mentally exhausted from chemotherapy, would prefer directly emailing their HCPs to inefficient phone communications (or lack of) with the Schedulers:

> [I] end up having to contact directly ANYWAY and so it's just easier to email [the nurse practitioner] and [the oncologist]…And again, I'm a Chief Technology Officer so email is you know…that's EASIER than you know {gestures holding up a phone} and going through the, yea getting on speaker phone and being prepared to go through five levels of menus before you get to the wrong person who actually could direct to the right person. (Male patient)

> I was with it, I was ready to leave Hopkins… I mean I was REALLY, REALLY DOWN…and if it wasn't for emailing [her oncologist] I would've gone some place else…Not getting any response and had to call three, four times, then they transferred me around to five, six different people…AND the thing is, when you're SICK like this, you don't FEEL like…ARGUING with people… (Female patient)

Hence the process of care coordination is in fact an issue of whether or not (1) MyChart is accepted as a communication tool, and (2) it provides a seamless platform between communication and action (= requesting appointment). Unfortunately, as discussed further in the next section, both HCPs and patients still consider email as the most useful and trustworthy method of communication that is highly preferred over MyChart's secure messaging. This notion is further enhanced by the organizational reliance on conventional methods (e.g. calling the Triage for prescription refills) and reluctance to adopting new workflows, which are manifested as HCPs' advices to patients that discourage the use of MyChart for care coordination and communication.

5.4.3 Communication with HCPs

As summarized in **Table 7c**, patients prefer emails to phone or MyChart secure messages. First, patients seemed to prefer the asynchronous communication method to phone because they do not wish to bother HCPs with symptoms and other concerns they consider (or hope) that are not urgent and that they are capable of handling on their own:

> I know how busy everybody is and I don't like to be DRAMATIC and I…I'd like to umm…unless it's an EMERGENCY and then I'll make the phone call but if it's not an emergency, I just feel like email works…they can respond at their own pace. (Female patient)

Patients also seemed to prefer directly emailing their HCPs to calling the Triage line for symptom management advice (despite most HCPs' recommendation to call Triage) since they want information that is as accurate and personally relevant as possible (as opposed to generic advice by the Triage nurse), especially when being upset and scared from unfamiliar symptoms or physical changes.

Despite the fact that MyChart's secure messaging is also asynchronous, patients continue to email their HCPs **(Table 8a)** simply because email has always worked with their HCPs and they know exactly where their email is going and who will be reading the message. On the other hand, patients choose not to use MyChart if they know their HCPs are not actively using MyChart secure messaging:

> So my sense is, at Hopkins I know some doctors use [MyChart secure messaging] and some don't…so if the doctor tells me they use it then I would do it but if they don't then…so it…I think it VARIES, but I'd just been using email for the most part. (Male patient)

Some patients were explicitly told by their HCPs to not use MyChart secure messaging because it does not work:

> I guess it was in December and I WAITED and I WAITED and I WAITED for response and I didn't hear back so I ended up CALLING [the doctor]…and he said "oh, don't use your MyChart," he said "use our direct emails" which is what I did. So, then that seems to be working much better. (Female patient)

Since patients are only interested in tools that definitely work with their HCPs, any implicit actions or explicit comments made by HCPs on their preference for a certain communication tool greatly influence the patients' preference and use of that tool:

> The email really seems to work with him, he LIKES emails…he doesn't like to TALK, he likes to TEXT…so it depends on your doctor, what your doctor likes… (Female patient)

In other words, patients' *Organization*-related factor (i.e. Communication infrastructure; being dissuaded from using MyChart secure messaging by their HCPs) seem to have a greater impact on their decision to not use MyChart than the other factors that are *Person*-related (i.e. preference for personalized information source) or *Technology*-related (i.e. greater familiarity with emails). **Table 10** lists HCP barrier to MyChart use, which, unsurprisingly, consists primarily of concerns related to the communication function of MyChart.

6. Discussion

6.1 Action Agenda

6.1.1 Maintenance of the Pool List

Given the degree of impact of HCP advice/comments about MyChart on patient's preference for a communication tool and its subsequent effect on the patient's use of care coordination features of MyChart, a preliminary action agenda must focus on alleviating HCP barriers to MyChart use. HCP dissatisfactions with MyChart secure messaging are mainly *Technology*-related, which seem to stem from the malfunctioning of the message

routing system based on the Pool list **(Figure 9, 10)**. A Pool is "a group of users who all receive a single InBasket message that requires action from any one person in the group".[50] According to a Triage nurse, who also uses the list for routing patient calls to HCP InBaskets **(Figure 8)**, the list in the system has not been updated since SKCCC went live on Epic:

> This NO updating has happened to the pool since we started in July so the nurse assignment changes, the new docs, none of that's there. So I have to try to remember who's NOT in the pool and add them to it [manually] and I'm not really good at that 'cause they never send me an update to who's doing what now either.

Since MyChart messages from patients are currently routed automatically to the outdated Pool list in the system, HCPs will either end up not receiving patient messages (and having to tell their patients to use email instead) or having to figure out who the message is for and re-route the message to the appropriate individual (adding work to already overloaded HCPs, increasing negative perception about Epic and MyChart).

Once the list is updated and secure messaging becomes functional, the organization needs to recognize that emails are in conflict with secure messaging and clarify organizational policy on the appropriate use of each tool in terms of MU requirements.

6.1.2 MyChart Experts

While some HCPs mentioned that they spend time explaining to their patients the benefit of signing up for MyChart and the patients' rights to access their own data, many floor nurses indicated that they often chose not to tell the patients much about MyChart due to

their own lack of knowledge about the tool, lack of time, and the fear that patient questions coming in through MyChart might increase their already overwhelming workload. To ease the burden of the floor nurses – while ensuring that all patients are informed of the new technology available to them – selected staff members could be trained as experts on MyChart, who will help patients sign up and assist with any technical questions on behalf of the floor nurses. In fact, a few members of SKCCC have hosted a series of MyChart education session called "MyChart Expert Table" where the staff demonstrated the components of MyChart to patients as tailored to their needs, answered technical questions, and assisted with sign-up by printing out activation codes and working through the process together.[51] Efforts similar to the Expert Table that are catered towards HCPs may be valuable in providing practice-specific tips on usage and in alleviating their unfounded fear of MyChart adding extra work.

6.1.3 Monitors, Blunters, and their Shifting Needs

Information-seeking behaviors of cancer patients have been known to fall into one of the two types proposed by Miller: *Monitors*, who actively seek information to cope emotional burden, or *Blunters*, who would only seek focused information or avoid seeking altogether to minimize distress.[52] Consistent with this theory, Groll et al. demonstrated that the type of information-seeking behavior is related to a patient's degree of acceptance and access to test results via EHR for surveillance of testicular cancer,[53] which suggests the importance of understanding patient coping styles in implementing patient portals.

Other studies have gone further to suggest that patient information-seeking behavior vary to a greater extent than Miller's dichotomy model of seeking vs. avoiding, such as the five health information-seeking behavior patterns proposed by Lambert et al[54,55] and the effect of temporality on newly diagnosed patients' information-seeking behaviors as they shifted from avoidance to seeking through the "journey of 'never-ending making sense' with ongoing discovery and new information needs".[56]

Patients in the current study also demonstrated variations in their information-seeking behaviors. Interestingly, the variation was also observed within the same individual, especially with patients who have had the experience of more than one recurrent/metastatic cancer or who have been on treatment for more than three years. Such patients – even if they were *Monitors* when they were first diagnosed – tended to avoid parts of their PHI (e.g. discontinue tracking scan reports to avoid shocking news yet continue following the CEA level), but at the same time became intense *Monitors* in terms of seeking information on alternative treatments and clinical trials. While they still valued credibility of sources with other information types, when it came to searching for treatments other than chemotherapy, they searched the Internet and acted on serendipitous information sources, such as an article in a magazine that the patient randomly picked up while waiting at her dental clinic.

If possible, future updates to MyChart should include a function where the patient could change the setting depending on their coping styles, such as to receive recommendations

on clinical trials or be offered links to a more credible and actionable information sources on alternative treatments.

7. Conclusion

The study contributes to the emerging field of "patient-engaged HFE" by applying the human factors principle – namely the SEIPS model – to systematically uncover the factors affecting usage of patient portals by all stakeholders and to propose an actionable agenda. By interviewing both the patients and the HCPs, in addition to identifying the organizational impact of HCP comments and actions on patient use of MyChart, the study revealed the potential root cause of such HCP reactions to MyChart as the technical dysfunction of the Pool list, as well as the lack of organizational policy that clearly distinguishes the intended use of tools that currently serve similar goals. Furthermore, not only did the study generate an action agenda applicable to the study site, the knowledge obtained through this study, especially the CRC patients' information needs, could contribute to future studies at other outpatient chemotherapy sites to design diverse tools, methods, or techniques to support CRC patients in managing their chemotherapy treatment.

Tables and Figures

Table 1. Patient-Engaged Processes Supported by MyChart

Patient-Engaged Processes	MyChart functions
Self-management of PHI and Appointments	• View, download, and print portions of medical record including test results (labs, radiology, and pathology), diagnoses, medications, and immunizations • Graph past lab results to view trend • View, download, and print AVS and post-appointment instructions • View, download, and print past and upcoming appointments • Proxy access to patient account by family members
Care Coordination	• Request appointments • Request prescription refills • Request update to medication and allergy lists
Communication with HCPs	• Secure messaging with health care team; MyChart offers the following pre-defined subject lines: Non-Urgent Medical Question, Prescription Question, Test Results Question, Visit Follow-Up Question, and Referral Request

Table 2. Operational Definitions of Initial Coding Categories

SEIPS Categories	Operational Definitions (Attributes/Characteristics)
Person	Education, skills, and knowledge; Motivation, goal, and needs; Physical characteristics; Psychological characteristics
Organization	Structures external to a person, which organize time, space, resources, and activity. **For HCPs**: Work schedules and assignments; Management and incentive systems; Organisational culture; Training, policies and resource availability; Teamwork (coordination, collaboration, and communication) **For Patients:** Communication infrastructure; Advice or recommendations from HCPs; Living arrangements; Family roles and responsibilities; Work and life schedules; Interpersonal relationships; Culture, social norms and rules; Financial and health-related resources
Task	Specific actions within larger work processes. Difficulty, complexity, variety, ambiguity, and sequence; Job control (autonomy) and participation; Job demands (e.g. workload, time pressure, cognitive load, need for attention)
Tools and Technology	Objects that people use to do work or that assist people in doing work. Usability, accessibility, familiarity, level of automation, portability and functionality
Physical Environment	Layout; Noise; Lighting; Temperature, humidity and air quality; Work station design

Table 3. Demographic and Clinical Characteristics of Study Participants

Patients (n=10)		
Characteristic	n	Mean (±S.D.), Median (range)
Age		Mean 58.2 ± 12.66 years, Median 55 (41−84) years
40 - 49	2	
50 - 59	5	
60 - 69	1	
70 - 79	1	
80 - 89	1	
Sex		
Male	3	
Female	7	
Ethnicity		
Caucasian	8	
African American	2	
MyChart status		
Active (managed by patient)	5	
Active (managed by caregiver)	2	
Not signed-up	3	
Non-professional caregivers at home		
None	2	
1 person	6	
> 1 person	2	
Years since diagnosis		Mean 3.0 ± 2.31 years Median 3 (2 mo to 7 yrs) years
< 1	3	
1 - 4	3	
> 4	3	
Unknown/Missing	1	
Current chemotherapy regimen		
FOLFOX	3	
FOLFIRI	3	
FOLFIRI+Cetuximab	1	
Vectibix	1	
Unknown/Missing	2	

Table 3. Demographic and Clinical Characteristics of Study Participants (Continued)

HCPs (n=10)	
Characteristic	n
Sex	
Male	3
Female	7
Ethnicity	
Caucasian	8
African American	1
Asian	1
Roles	
Nurse	5
Physician	2
Triage	3

Table 4. Qualitative Data Overview

	Patients	HCPs
Number of Transcripts	10	10
Interview length (mm:ss)		
Mean (±S.D.)	23:13 ± 8:27	19:11 ± 8:03
Median (range)	25:01 (10:17 − 34:14)	16:54 (10:07 − 32:53)
Number of Passages Coded as Meaning Units		
Processes	286	300
Work Systems	901	615
Person	452	232
Organization	125	195
Task	175	71
Tools and Technology	149	116
Environment	0	1

Table 5. Patient Information Needs

Patient information needs	Description	Example
Test results	• To track blood work, especially the CEA number • Meaning of scan reports	"there's only one number in there that I look at... and that's the CEA indicator, which is an indicator for colon cancer... So...and um I watch that so...hopefully that will be going down" "...[patient's daughter] really really helps me with [terminologies]... so we can at least understand what the CT scan is saying-- but I kinda like to see what the CT scan says… so I think kind of keep track of it…"
Side Effects	• Potential side effects of a new regimen • Uncertainty about symptoms being experienced • How to manage unusual symptoms • Managing unexpected side effects and planning daily life around them	"when I first started what helped me was my nurse... actually gave me EXACTLY what symptoms to expect... and WHEN they would hit you... it helped to kinda know what was gonna happen... 'cause it's SCARY the first time…" "I had a sensation in my mouth which was more of a side effect from one of the drugs so that was just a question just to make sure that was normal…" "how to manage the rash... was probably one of the side effects I was least prepared for… I looked up as much as I could about this type of drug and I looked for blogs by patients who'd been on it" "...how THIS particular treatment's gonna go and how I'm gonna react... the BIGGEST problem I have in terms of... of sort of PLANNING..."; "I could be four treatments in and have a different reaction to the treatment...but I have found that...it pays to pay attention to my own experience."
Appointment	• Scheduling next imaging test • To check or confirm next appointment • Reconciling conflicting appointment information	"when we're trying to figure out his schedule... if we're trying to figure out the timing for the next SCAN so you can evaluate the effectiveness and progress of the disease" "a lot of times they'd forget to call me and tell me what time the next chemo is, so I have to call to get that information" "it was just more of like, this is showing up on MyChart but I don't have that appointment... and then we were able to reconcile that [by phone]"

Medication	• Keeping track of different medications	"I don't take Norvasc anymore, I just take the um Metoprolol and um... and I was on a diuretic... well the diuretic's not really working either so I stopped that"
	• How to take the medication	"I'm taking... five or six imodiums three times a day, and I thought "this is TOO MUCH" and it started to get to me... but [oncologist] said "Oh you can take all the imodium you want"... that helped, it reassured me."
	• Keeping track of refills	"I keep tabs on and make sure... you know, "hey did you need to get another prescription?", fill it while we're here… which is GREAT 'cause that saves me a trip, having to go out to the pharmacy going home."
Home care procedures	• Managing the infusion pump	"...I get my chemo at home... 'cause [homecare nurse] would come in and put the... chemo-- give me the PURSE for today, tomorrow, and half of the Wednesday... so like I say, I'm ok. I'm ok."
	• Manage the port	"they taught him how, the home care nurses, taught him how to disconnect after the 46 hours of the 5FU"
	• Managing the ostomy bag	"...the nurses…kinda taught me through different techniques to use to prevent the leakage. It's better."
Plan of care	• General course of treatment	"I found [a book given by his oncologist] really really helpful for each of the stages so it helped a lot with surgery... after surgery... and then getting ready for chemo."
	• What the next option/treatment is once the effectiveness of current Tx is lost	"I'm just concerned with how am I doing, how and what are we doing about it…"
	• What to do after completing chemotherapy	"You know just trying to find out what type of medicine or ADDITIONAL information on vitamins I could use once I FINISH this... will I need to, you know, use something ELSE to keep the cancer out of my system"
Alternative Treatment	• Novel treatment; options other than chemotherapy	"anything I can find that is new and aggressive... you know? why not TRY it? It may not help me but at least it might..."
	• Clinical Trials	"I've looked up, I've gone into clinicaltrials.gov…"
Where	• Need to know where	"to know when you go into a system and everything is there is great"

information could be found	personally relevant data and information could be found, accessed, and used when needed	"I love having access to them ... I mean I don't understand a LOT of it but [medical family members] understand it so it's just helpful to have somebody else read it ... just helps us understand what is happening, that we didn't completely feel like we were in the dark"
Finance	• Insurance and billing	"[husband] does take good care of all the bills... {sighs} the million pieces of paper that Johns Hopkins keep sending to you {small laugh}, insurance company..."
Treatment Effectiveness	• Uncertainty about effectiveness • Perceived loss in Tx effectiveness	"...every day we have concerns... whether if the medicine's gonna work... we wonder what is going to be NEXT... sometimes we wonder how... how many other methods we could DO..." "I knew that treatment wasn't-- had lost its effectiveness and we needed to do something else... and that's why I pushed for the scan and the discussion about changing to this {points to the IV bag}"
How to coordinate care	• Coordinate care between chemotherapy and other departments/institutions	"We had to resolve a conflict... an issue between the radiation and chemo... and we needed to get a hold of _[oncologist]_ and we couldn't do it... then he finally called…"
Contact Information	• Having multiple numbers to call	"so there was... for the chemo, it was clear... I just had surgery before the chemo too so like in some case so I'm not sure if I should be calling the surgeon's office or I should be calling the chemo…"

Table 6. HCP-Perceived Patient Information Needs

HCP-perceived pt information needs	Description	Example
Side Effects	• Potential side effects of a new regimen	"e-mail questions are follow-up questions to a visit, say, "you spoke to me about FOLFOX and Avastin and now I have some questions more about side effects of Avastin, can you explain more in detail what those are.""
	• Uncertainty about symptoms being experienced	"...a patient developed diarrhea, "is this okay?", or "I thought my blood counts would be better at this point" or you know, "I didn't think this would cause a rash""
	• How to manage symptoms	"people may call for increased pain, or pain that's not controlled... unable to eat, nausea, vomiting, diarrhea…"
Test Results	• To see if blood counts are good to come in for treatment	"when they come up here… [patients'] biggest concern is making sure that they are good to go for treatment because… if their labs are out of whack and they can't get treatment they do become very concerned regarding that."
	• Meaning of the test results, to track treatment progress	"some people ABSOLUTELY, JUST... CAN'T, GET, AWAY, from it... like it is their WHOLE life, what those numbers are, what that scan says... and it's a shame because that's not what it's supposed to be... But I guess that's all they can hold on to..."
Appointment	• Requesting new appointment	""I would like to start treatment on this day, can you set that up?""
	• Changing appointment	"sometimes about scheduling changes or delays that [patients] would like to put in."
	• Appointment reminder	""I can't remember what day I was supposed to see you", "am I supposed to have labs on this day""
	• Confirming appointment	""I haven't gotten my schedule yet" or "this schedule seems to be in conflict with what I was told before""
	• Receive updates on appointment changes	"I try to have options available for them when I call… not always a problem, but some people come from a great distance."
	• Coordinating with personal life	"There is a lot of talk about scheduling… patients obviously are trying to live their lives so they're coordinating all this stuff with their personal life so if things come up and

		things get changed…"
Medications	• Prescription refills • How to take the medication	"when they call triage, like today I've had a bunch of refills" "A lot of times we tell them they can take Imodiums so they read the box, but what we tell them [about how to take it and] what the box [says] they don't match, so you have to do that re-teaching and let them know how to take it."
Where information could be found	• Need to know where personally relevant data and information could be found, accessed, and used when needed	"And again they may not understand what it MEANS, but at least uh, you know, where the labs are, where the scans are, where their report-- where they're clinic visits are... all that stuff"
Contact information	• Having multiple numbers to call • Contact for different stages of care • Off-hour contact information	"sometimes they say they called but it depends on who they called and where because they have a lot of numbers." ""Do I call this person?! Do I call that!?" and try to get everybody together so that you can get your treatment" "Let's say they're having an issue that they may need to call the on-call doctor. I make sure they have that number and I document it, that the patient said they had their number 'cause I don't want anybody to feel neglected after we're closed."
Alternative/ Complimentary Treatment	• Other treatment options • Vitamin/Herbal supplements	"maybe a third of patients would do some sort of intensive research to think about other options or ask questions that they've got information from outside sources" "A lot of times it's a simple question like "Can I take vitamins if I'm on this medicine?", "May I take a herbal supplement if I'm doing this?""
Treatment Effectiveness	• Expected effecvtiveness • Uncertainty about effectiveness	""what does this medicine do"... it's asking me, "is this going to cure me or is this to stop my cancer", or what is going to-- or "is it going to make me sick, is it going to put me in the hospital?"" "…they just, they don't feel well and that they don't think it's working, "is it working?", there is a lot of anxiety around it so it's a lot of that talk as well"

	• Effects of missing treatment	"They're concerned that if they miss a treatment that things are gonna progressively get worse for 'em, so that's one of their main concerns."
MyChart	• Technical issues	"some of them say they can't find stuff in it but most, the only patient-- things patients say "well I can't get on today do you know if it's down", I have no idea if it's down."
How to coordinate care	• Coordinate care between chemotherapy and other departments/institutions	"...their doctor visits that they have and how that should be integrated with their chemotherapy..."
Diet/Nutrition	• What to eat during treatment	"Diet issues are not usually something that's very helpful to our patients although you can try to have them try a BRAT [bananas, rice, apple sauce, toast] diet because of the etiology of the diarrhea, usually that isn't really good for them"
Financial	• Co-pay information	"LOTS of questions about co-pays, which I know absolutely nothing about umm but has nothing to do with me, that has to do with the pharmacy and their insurance plan..."

Table 7a. Sociotechnical Factors Affecting Patient MyChart Use in Self-Management of PHI and Appointments

Patient-Engaged Process	Available Tool/Tech to Achieve Tasks	Main Tool/Tech Used	Sociotechnical Factors			
			Patient	*Task*	*Organization*	*Tools/Technology*
Self-management of PHI and Appointments	• MyChart • Print-outs from HCPs	MyChart	• Patients highly value autonomy and sense of having control of their lives • Want to be aware of what is going on so that they could have a 'work-life-treatment' balance • Knowing where data and resources could be found at all times is reassuring • Test results could be upsetting – patients gradually develop their own coping strategies	• Patients need to organize and keep track of: - Test results - New appointments • Understand what the test results mean in terms of plan of care • Understand "what information scares me" and strategize which results to see or not see • Share information with others (e.g. HCPs at another institution)	• Advice from HCPs: Keeping track of test results is important and it will help patients come prepared for physician visits • Patients' psychological burden (e.g. depression, being upset from results) are reduced by having their family members taking part in their information management	• Email-reminders and notifications are useful in tracking results and appointments • Portability of data allows easy sharing • Proxy access supports information management by family members • The tool aligns with traditional method of receiving printouts from HCPs and filing in binders, though release of test results sometimes are delayed

Table 7b. Sociotechnical Factors Affecting Patient MyChart Use in Care Coordination

Patient-Engaged Process	Available Tool/Tech to Achieve Tasks	Main Tool/Tech Used	Sociotechnical Factors			
			Patient	*Task*	*Organization*	*Tools/Technology*
Care Coordination	Scheduling or Changing Appointment: • MyChart • Phone (Schedulers or HCPs directly) (• Email HCPs directly)	Email/ Phone	• Physically and mentally drained from side effects – no energy to deal with inefficient communications	• Patients need to: -Get hold of HCPs -Figure out availability of HCPs • Request new appointment or reconcile conflicting appointments with Schedulers	• Epic/MyChart are still new so the organization as a whole continues to rely on conventional communication methods (e.g. Schedulers may call patients about new appointments – Fig. 7)	When it comes to getting hold of HCPs and figuring out their availabilities: • Patients see email as efficient: enables direct contact with HCPs with reasonable turn around time • Patients see phone (Schedulers) as having bad response with inefficient "phone tags" • MyChart is only used to get hold of HCPs whom patients don't have their email addresses
	Rx refill: • MyChart • Phone (Triage Call) (• Email HCPs directly)	Phone	(N/A)	• Pick up refills on the way to/from clinic to avoid extra trip	• Advice from HCPs: Call Triage for Rx Refill • Family members help with transportation to/from clinic, as well as requesting refill and pick up on the day of chemo	(N/A)

Table 7c. Sociotechnical Factors Affecting Patient MyChart Use in Communication with HCPs

Patient-Engaged Process	Available Tool/Tech to Achieve Tasks	Main Tool/Tech Used	Sociotechnical Factors			
			Patient	*Task*	*Organization*	*Tools/Technology*
Communication with HCPs	• MyChart • Email HCPs • Phone (Triage Call or HCPs directly)	Email	• Prefer to deal with side effects on their own as much as possible based on personal experience (want to have sense of control) • Don't want to bother busy HCPs, but want to be reassured by HCP advice • When unfamiliar, physical changes occur, it is upsetting and scary • Only want minimum necessary, personalized information	• Find an accurate, personalized answer to: - Test results concerns - Medication concerns - Symptom management • HCP as primary information source (as opposed to generic sources e.g. hand outs, Triage Call) • Getting hold of HCPs via method that definitely works	• Advice from HCPs: Use Triage Call (Fig. 8) for symptom management • HCP Individual Practice Variance: Some HCPs give out email addresses and encourage patients to use email (some explicitly mention not to use MyChart secure message), while some do not give out email and tell patients to call Triage for any questions	• Email: Easier, works better, and direct contact with HCPs with reasonable turn around time • Phone: Only for emergency, otherwise email; confused about which number to call • MyChart: Unclear where the message is going; sometimes HCPs do not receive the message

Table 8a. Patient Facilitators to MyChart Use

Patient Facilitators	Description	Examples
Having access to PHI and Appointment information	• To track blood work, especially the CEA number • To check or confirm next appointment • Knowing having access to scan reports (often times require physician guidance or external research to understand the meaning of scan reports)	"I look at my graph of my CEA numbers so that I know where THEY have been before I go see _[her Doctor]_... and then I kinda know what he's thinking before I go in... and that helps a lot." "as far as looking at my appointments and keeping track, that's g-- that's working for THAT" (*Refer to "Portability of data"*)
Reminders and notifications	• Help patients keep track of appointments and new results or messages posted in their MyChart without being online 24/7	"next day I get an email saying it's there. So I know when to check… so VERY, VERY useful."
Getting hold of HCPs	• Useful to get hold of HCPs (especially NPs and RNs) whom patients don't have direct contact information (e.g. email)	"you have…the people from surgery and other disciplines that all are a part of the team that I might not have their e-mail addresses for so if in that case maybe I would be more likely to use the portal"
Portability of data	• Enable information sharing (e.g. printing scan reports for other doctors) • No need for physical folder and papers	"I think to me, having that access is a good thing... I know what's too scary for me at this point and... you know in the beginning before I had a lot of surgeries I did want to see all of my scan reports... I don't really look at the scans [now], but for me it's useful to be able to go in and... if the report hasn't been made available [between institutions] I can print it for my team." "I DEFINITELY would use it, I DEFINITELY would... because then I wouldn't have to have all these paper around! That'll be so much easier…"

Table 8b. Patient Barriers to MyChart Use

Patient Barriers	Description	Examples
Use email instead of MyChart secure message	• More comfortable/used to using email • Encouraged by HCPs to use email instead of MyChart secure messaging (either explicitly told or implicitly through action) • Unsure where or to whom the message is being routed to; generic and impersonal	"Email's just easier... I don't have to go to [MyChart site] and get to another site and develop--and remember YET another username and yet another password…" "I don't go through MyChart [for] emails anymore because [the doctor] said that it didn't work very well for emails and that he often didn't get the ones from patients so I don't... I don't email anymore on that 'cause... I didn't get any responses" "I have [her care team]'s email, so if I wanna send HIM an email... if I send it in there [MyChart], I don't know WHO's getting that email"
Looking at data creates anxiety	• Often times patients (especially patients with >4 years since diagnosis) do not look at scan reports on their own because they know the reports don't help but only increase their anxiety	"like the CT scan results or certain... I don't... I don't look... I don't even open them up because... they... they upset me. They put like... pictures in my mind that I don't want it to be there..."
Delay in information posted to MyChart	• Test release is slow (possibly depending on whether or not the HCP manually releases the result) • Some tests are never released (the patient doesn't know why - whether it is because the lab was done outside or the physician intentionally blocked it from release)	"I already have my blood work TODAY, we got the results right here on a piece of paper and his labs are in here... it won't go on [MyChart] for a WEEK. They're VERY slow." "I use it to check lab work when that's been released... and sometimes lab work is released, sometimes it's not released so…"
Barrier to sign up: Process is not clear	• Patients having misconceptions about the sign up process (especially about Activation Number) due to lack of guidance	"I got into it, but it asked for the umm my ID number and I had it on one of the bills or something so I put it in, but it just never would let me get into it"

Table 9a. HCP-perceived Patient Facilitators to MyChart Use

HCP-perceived Patient Facilitators	Description	Examples
Having access to PHI and Appointment information	• Tracking labs, scan, and appointments	"They use MyChart to look at their CT Scans, look at their blood work, find out their appointments...which is... good and bad... because if they see something on the CT Scan that was not... SAID to them, then they freak out and then we get the phone calls [at triage] for that so..."
	• Offer autonomy	"we HAVE to-- it's, it's their right, we have to give-- even though I don't necessarily think it's the best thing for some people {tone rise} I have to provide them with the information-- what they choose to do with it after that is up to them."
	• Anxiety towards physician visit could be lessened by seeing results beforehand	"maybe not the details but if you knew that ok overall this is going to be a good conversation because my scans look better... I think that changes the mentality coming into the clinic and I think that would clearly have a means of reducing anxiety and stress for a visit-- so I think from that side MyChart can really help"
Scheduling through MyChart easier than phone	• No need for a long hold time on the phone or phone tags	"overall it's more the scheduling thing that people have embraced because of the problems they had in the old systems"
Portability of data	• Enable information sharing	"I think there is some great value in the... sharing of all this information so its that patients who or family members and friends who aren't here can look at records and can try to make sense of them and ask next questions."

Table 9b. HCP-perceived Patient Barriers to MyChart Use

HCP-perceived Patient Barriers	Description	Examples
Looking at data creates anxiety	• Some patients want to avoid information that they don't understand because they don't want to worry; prefer HCP guidance and not look at it on their own • Puts extra responsibility to already overwhelmed, worried patient	"I think some don't like [seeing PHI on MyChart]... some of the stuff doesn't make sense to them for instance and so they don't want to worry about things that they don't understand. I get that a lot saying "well I figure that if it is important you tell me" that kind of response" "now they have to look at MyChart-- or they are encouraged to look at MyChart and look at their information-- for some it's like too much right, they're like I have enough things to worry about as is so I don't want to take that extra responsibility"
Use email instead of MyChart secure message	• Easier and used to using email than MyChart secure message • Already have HCP's direct email address	" the majority of communication is via e-mail... I would say…probably over 50% via e-mail or 60%, maybe 30% calls and maybe 10% by MyChart..." "they don't necessarily maybe think should I contact him via MyChart or via e-mail so he gave me his e-mail why not just use that... so."
Skepticism towards MyChart	• Accuracy of data • Unsure of what MyChart could do or how to use it	"they'll come with the appointment time that they already had when they left and they dismiss the MyChart, what it will say on MyChart." "They'd say "why don't I get a text or an e-mail that there's a new message in MyChart, I have to keep going into MyChart to check on the response..." so… I think there is some skepticism there."
Certain medication refills cannot be requested on MyChart	• e.g. Narcotics	"narcotics they have to have a handwritten script… so they can't get it through like the electronically through the pharmacy so they have to have that physically scripted and delivered to the pharmacy"
Used to HCP handing test results		"they don't seem that enamored with using [MyChart] to look at their results when they're used to us giving them a print out"
Delay in information posted to MyChart	• e.g. Appointment information	"I've found that the patients' MyChart information is OFTEN a day behind"
Barrier to sign up: Lack of access to computers/internet		"Some people don't have access to internet… Some people are not computer savvy-- I mean I try to do whatever works for them"

Table 10. HCP Facilitator and Barriers to MyChart Use

HCP Facilitator	Description	Example
Helps patient ask better questions	• Patients (and family and friends) could use MyChart to understand plan of care, prepare for physician visit, and ask better questions	"[offering patients access to PHIs] can only help in conversations…to have the patients have family members and friends informed…and decisions are much more based on a shared conversation, as opposed to me just telling somebody "You know your scans look like so""

HCP Barrier	Description	Example
Unfamiliarity and Problems with MyChart Secure Messaging	• Lack of training on MyChart functions	"I should probably access it myself and get to know it but I haven't done so yet... Haven't thought about it very much to be honest."
	• Easier to use email than MyChart secure message	"it's hard to replace the e-mails… we're much more comfortable with them and…there is much more capacity and capabilities with e-mail unless there is something about MyChart that I don't know about that again, could help us."
	• Don't know how the secure messaging works on patient's end	"I don't know from OUR end what they're looking at."; "can they put in physician, nurse, mid level provider [when sending secure message]… usually when I see the MyChart e-mail or communication it is usually just addressed to me..."
	• The Pool list, which is also used for triage notifications, is not up-to-date	(Triage nurse) "this NO updating has happened to the pool since we started in July so the nurse assignment changes, the new docs, none of that's there. So I have to try to remember who's NOT in the pool and add them to it and I'm not really good at that 'cause they never send me an update to who's doing what now either."

	• Don't know how the secure messaging works (routed) on HCP's end (e.g. to whom the message gets routed) • Unsure how to forward patient responses to entire Pool again once a member "takes" the initial patient message • Some HCPs confuse MyChart messages with other InBasket messages (e.g. triage notifications), so any problems experienced with other InBasket messages affect their perception of MyChart messaging	"I don't think the patient can directly [message the Pool] though. I don't think they can-- I don't know, maybe they can, but I've never had it happen to me that way." "one thing that does end up happening if I reply to message in MyChart then the patient can just keep on going on that thread, and it's just to ME. It is not to my pool anymore because I have replied to the patient and I think I can probably reply to everyone..." "in our OLD system [OCIS web] we could see that the patient called... patient would come in and say " you know I called the other night" and I would go "yea I know, bla bla bla"... now I DON'T know so I feel VERY... out of TOUCH with that whole triage system with MyChart..." "[talking about triage notification] It's too much... you know I think that clinicians and providers are just very busy and... uh from that aspect I don't like MyChart quite frankly... it is just too much to read... umm I, I don't like that aspect of MyChart"
MyChart increases HCP workload	• Don't have time to answer questions via MyChart secure message; triage call should take care of those questions • Don't have time to teach patients about MyChart	"we don't have the TIME or the... just to be able to look through the MyCharts and say "oh is this serious, is this not serious? Do I need to call them back today?" That's like... that's what the triage line is for…" "...I have 8 patients a day who need thousands of chemotherapy...I REALLY think sometimes a lot of this teaching is more than what we should be doing... a lot of it's technical so they should have somebody sitting down with them and go through the technical aspects of these things..."

Communicating through MyChart is not the norm yet	• Epic/MyChart are still new so the organization as a whole continues to rely on conventional communication methods	"I don't think us as a center yet are relying on MyChart as a... like a big communication tool OUT to the patients, I think we're still using phone calls for the most part"
Accidental release of test results	• Test results ordered by other department could get released prior to discussion with oncologist	"[Oncologist's patient] got a PET scan as part of [a clinical] trial and the PET scan revealed all these bone lesions that they hadn't known about and WE hadn't known about, but I hadn't ordered the test, it was done as part of a research study so I didn't get cc-ed on the report, but it pops up on their MyChart so then the daughter was like freaking out "what about this PET scan!" I was like "what PET scan!? I don't know!" so had to go into chart and "oh crap you've had a PET scan" ...and it was BAD so..."
Addressing Rx refill request is easier/better via triage	• Prefers refill documentation done by triage	"I don't find [addressing refill requests coming in through MyChart] EASY, I don't know that the physicians even find it easy... I think it's easier to call the triage {tone rise} it's easier for us to have that documentation THAT way than to go through MyChart... so I don't know if my physician uses it... I don't use it at all."
Skepticism about patient health literacy	• Access to PHI may help increase patient's sense of control, but not sure if they actually use those information	"[Access to PHI] gives them more of a sense of control but I'm not sure when they are actually viewing it at home, like how much... how useful that information is"

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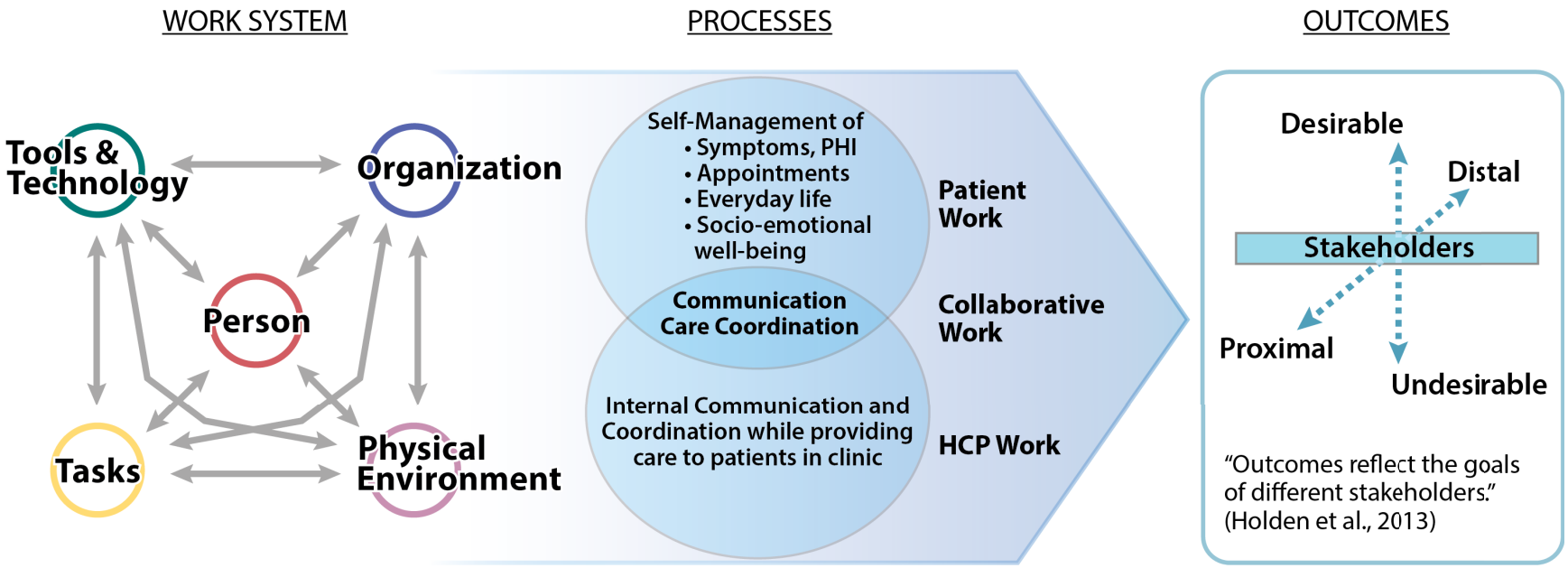


Figure 1. Modified SEIPS Model

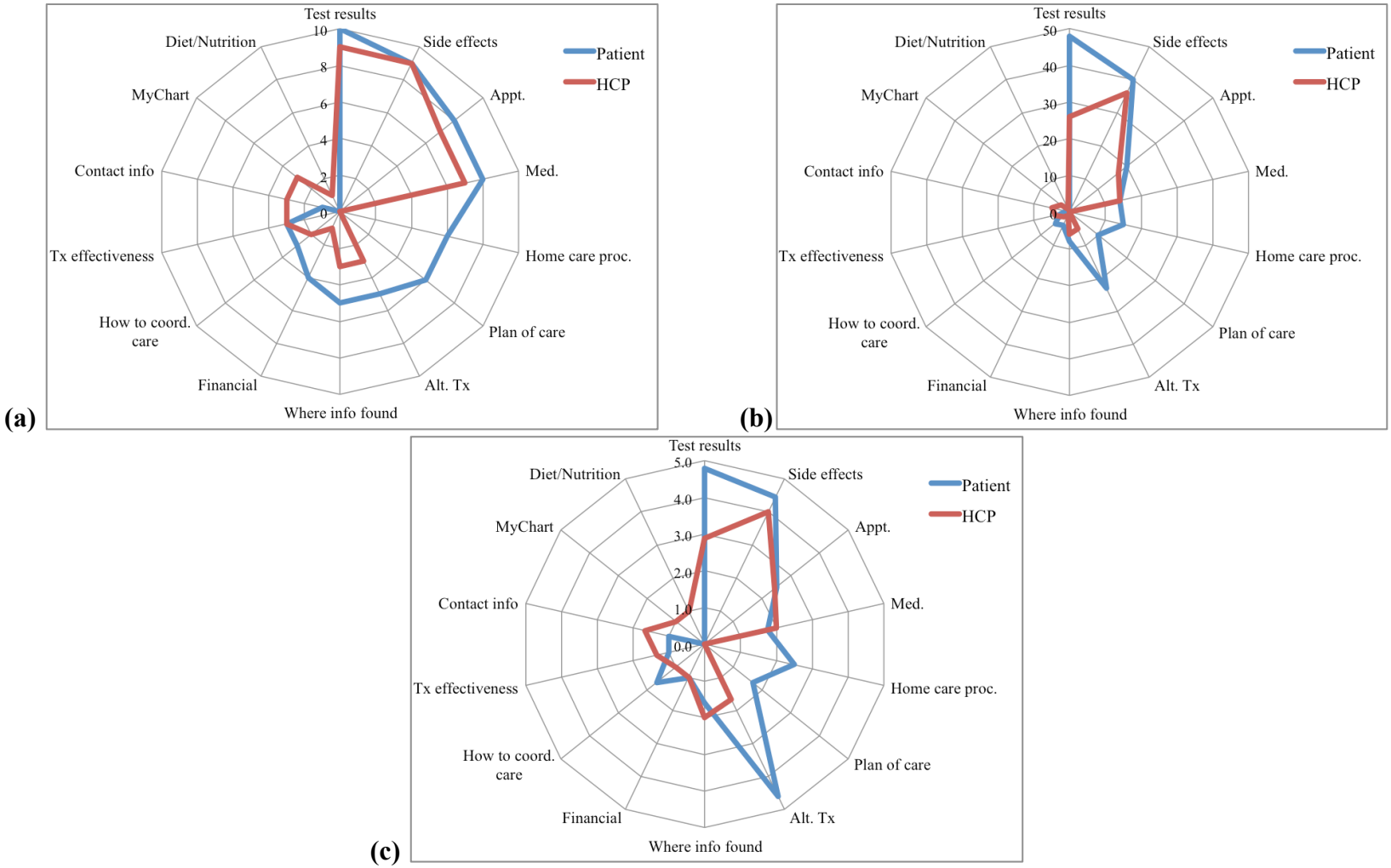


Figure 2. Patient vs. HCP-perceived-patient Information Needs by number of respondents (a), number of mentions (b), and average number of mentions per respondent (c).

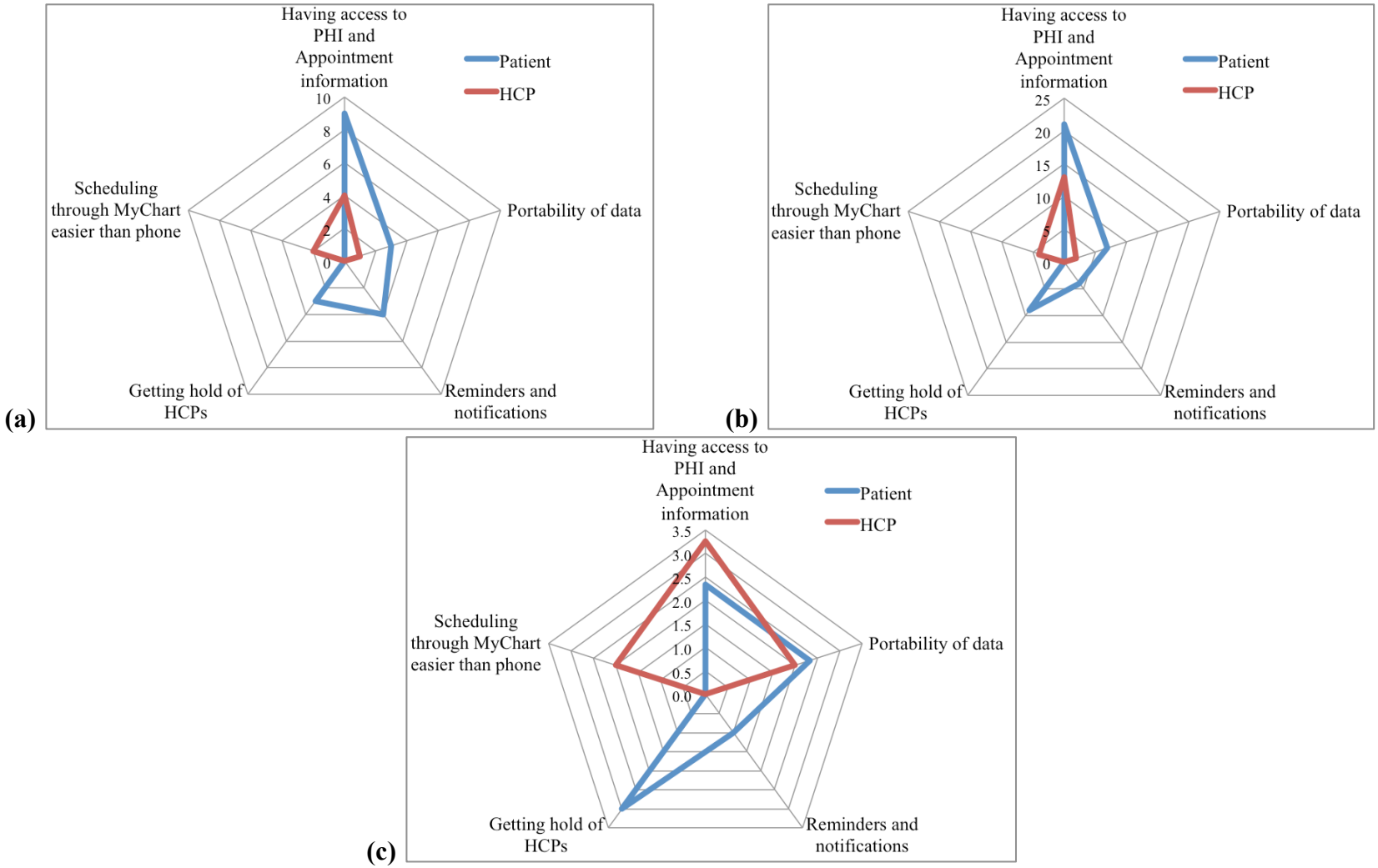


Figure 3. Patient vs. HCP-perceived-patient Facilitator to MyChart Use by number of respondents (a), number of mentions (b), and average number of mentions per respondent (c).

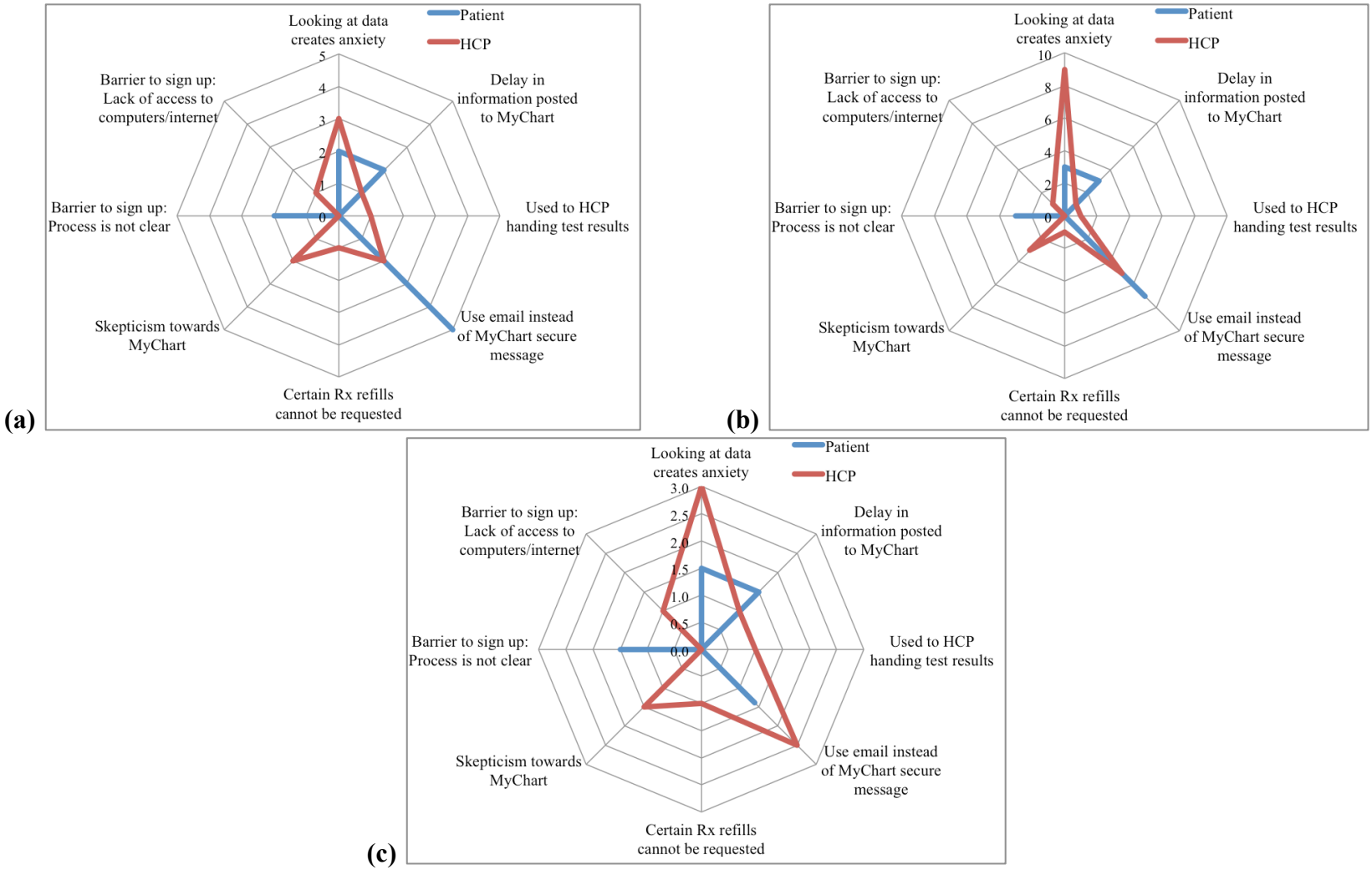


Figure 4. Patient vs. HCP-perceived-patient Barrier to MyChart Use by number of respondents (a), number of mentions (b), and average number of mentions per respondent (c).

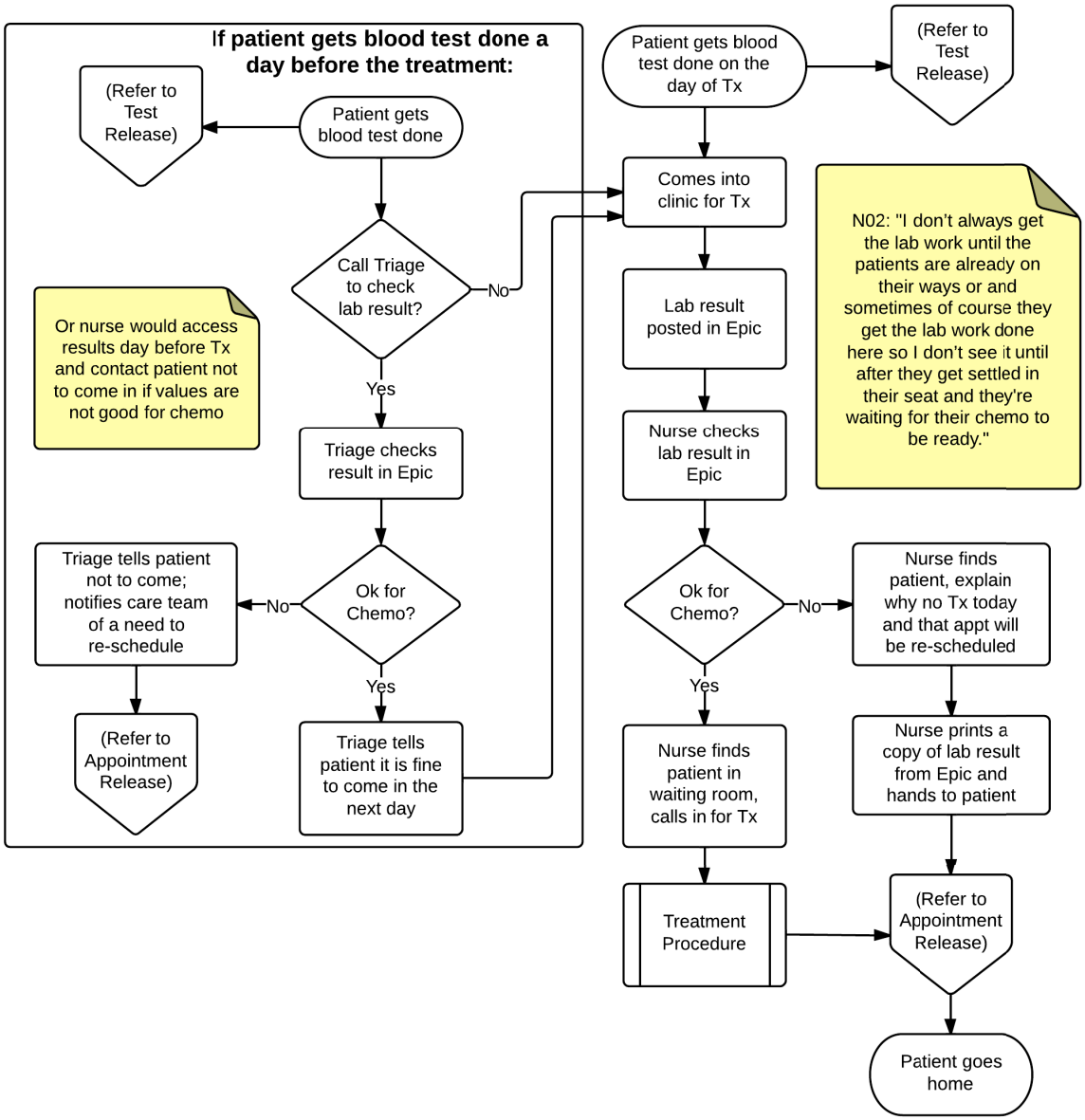


Figure 5. Routine Chemotherapy Visit

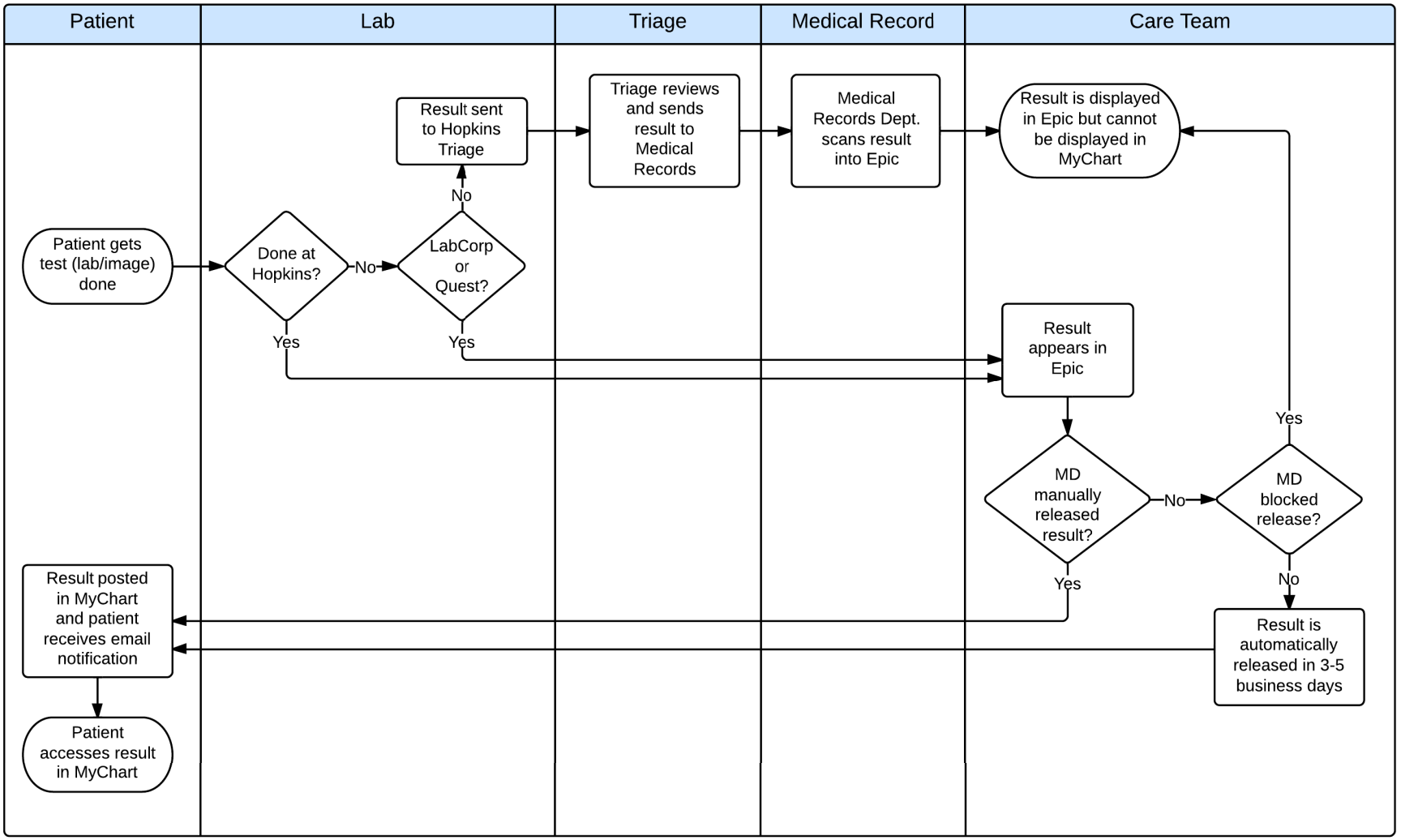


Figure 6. Test Release to Patient

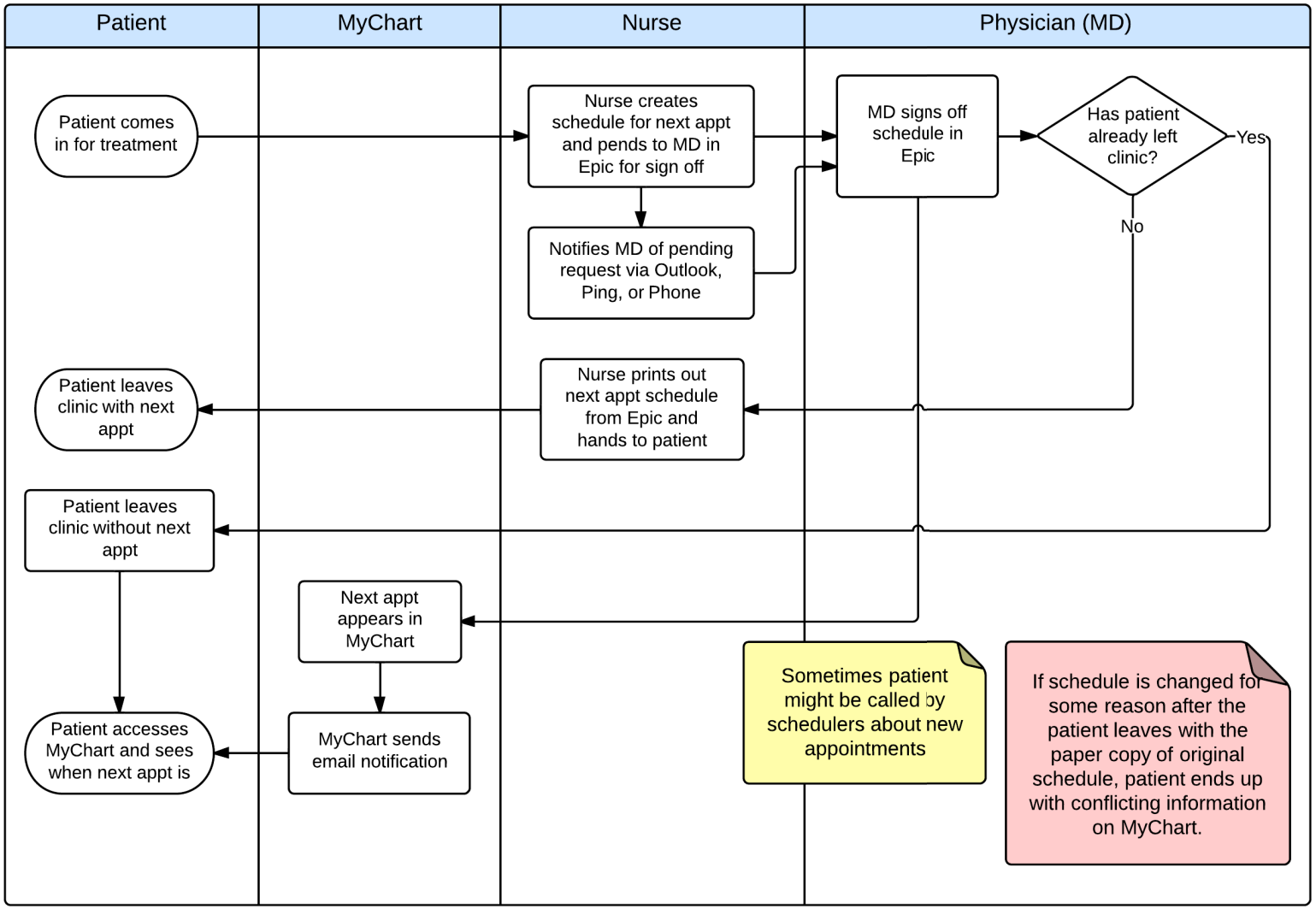


Figure 7. Appointment Release to Patient

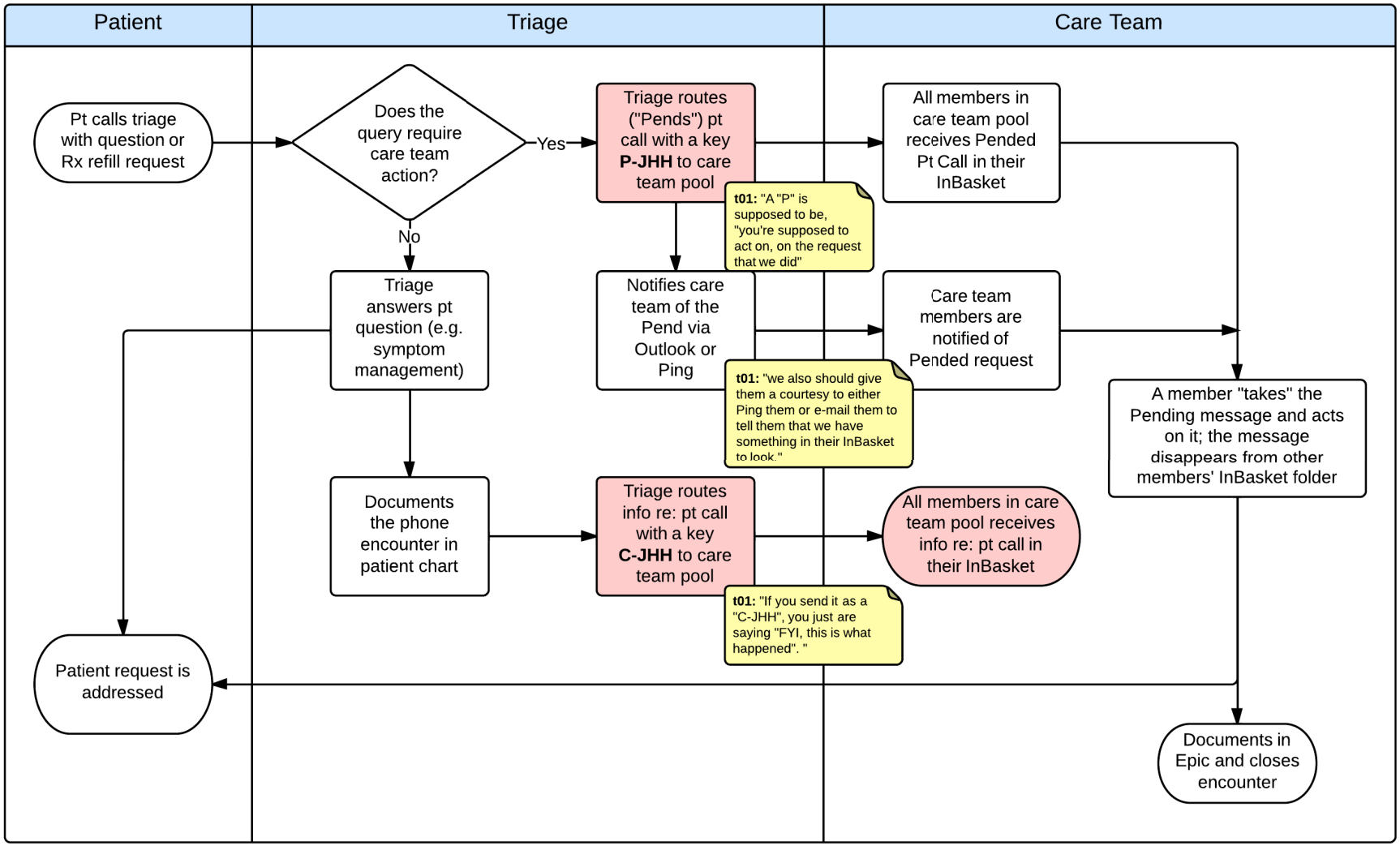


Figure 8. Triage Call: Care Coordination (Rx Refill only) and Communication

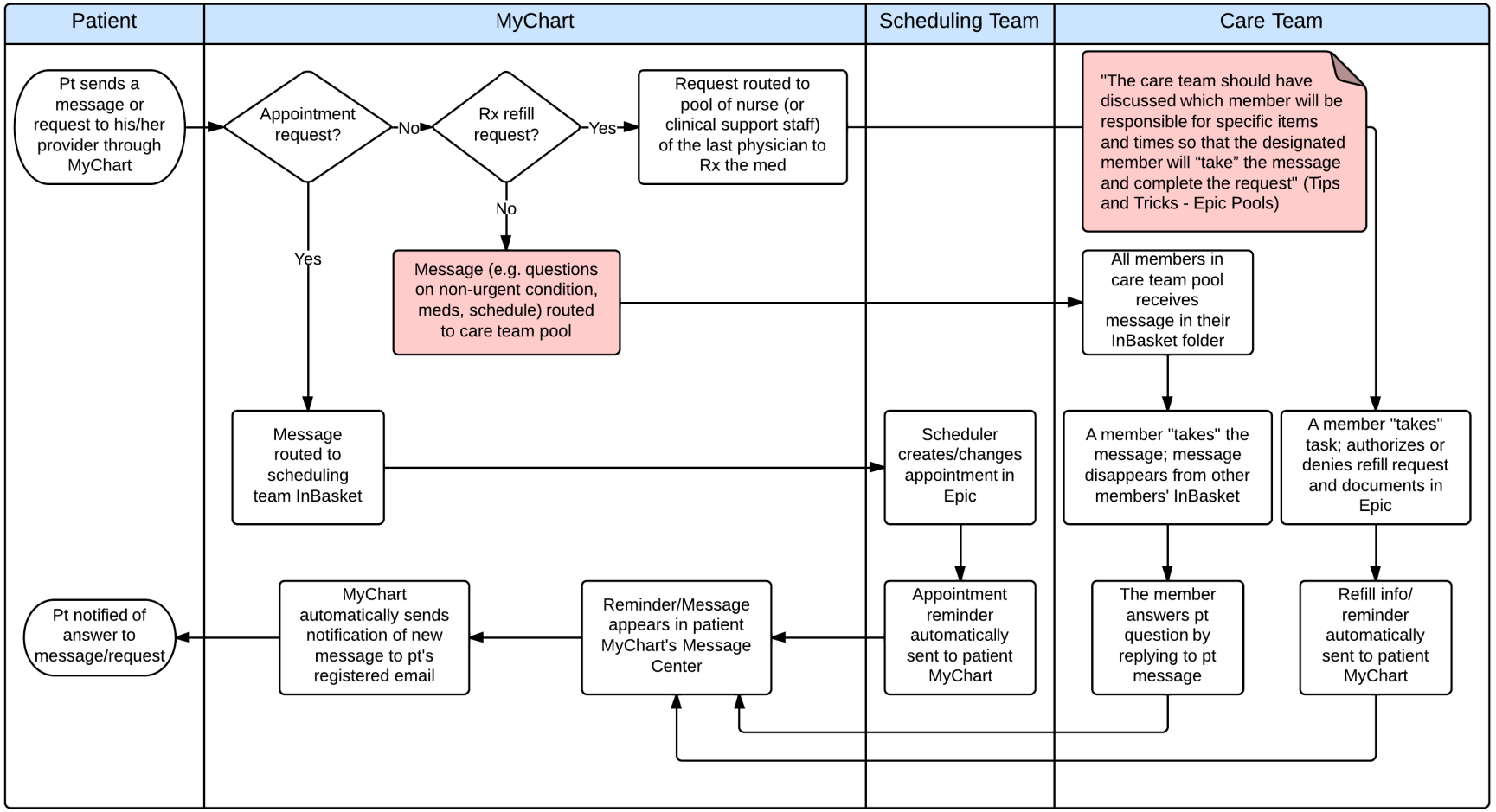


Figure 9. MyChart: Care Coordination and Communication (Secure Messaging)

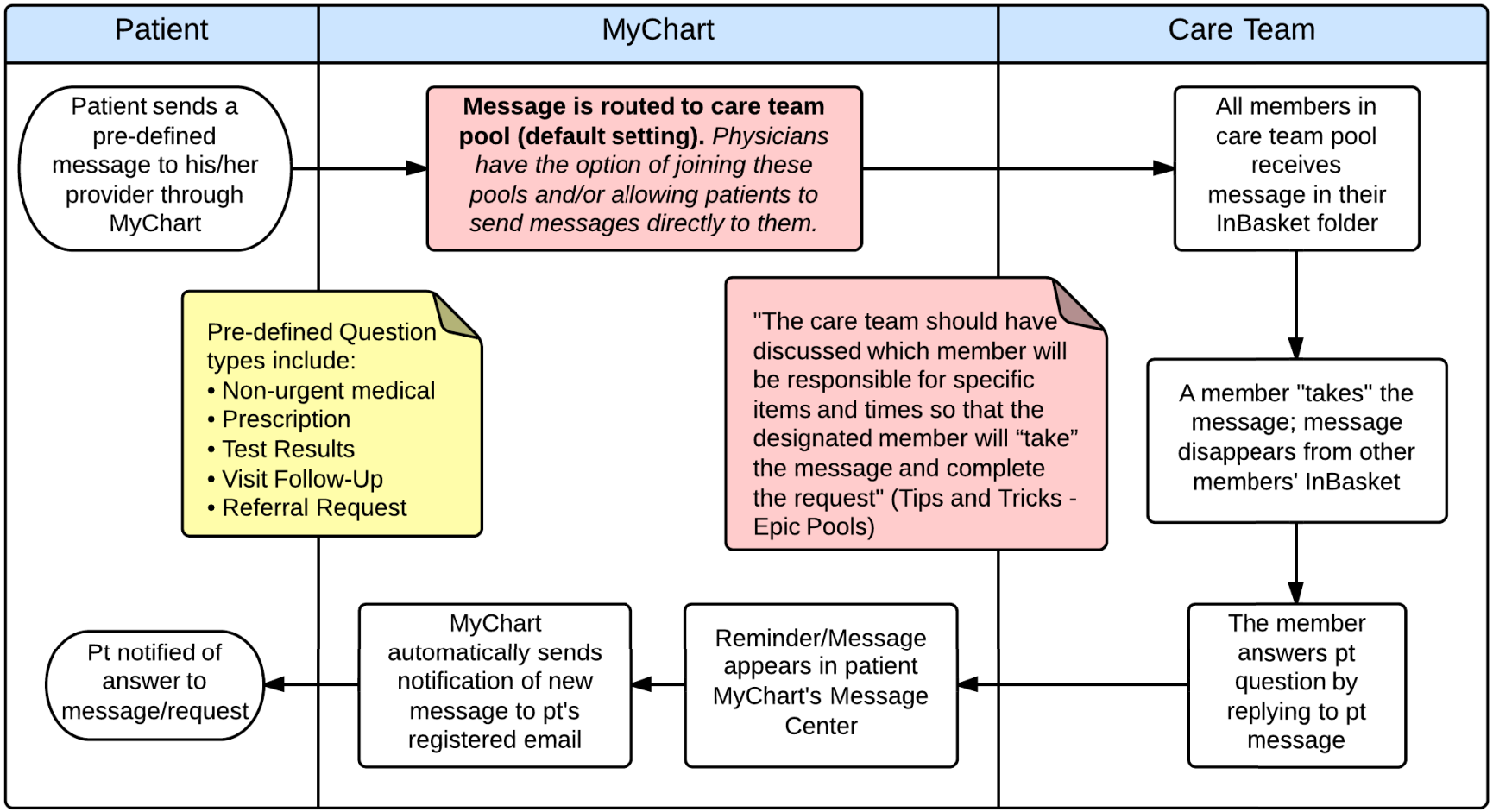


Figure 10. MyChart: Communication (Secure Messaging)

References

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academies Press; 2001:1192.

2. Hillestad R, Bigelow J, Bower A, et al. Can electronic medical record systems transform health care? Potential health benefits, savings, and costs. *Health Aff (Millwood)*. 24(5):1103–17. doi:10.1377/hlthaff.24.5.1103.

3. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207–14. doi:10.1377/hlthaff.2012.1061.

4. Agarwal R, Khuntia J. *Personal Health Information Management and the Design of Consumer Health Information Technology: Background Report. (Prepared by Insight Policy Research under Contract No.HHSA290200710072T). AHRQ Publication No. 09-0075-EF*. Rockville, MD: AHRQ Publication; 2009.

5. Finkelstein J, Knight A, Marinopoulos S, et al. *Enabling Patient-Centered Care Through Health Information Technology. Evidence Report/Technology Assessment No. 206. AHRQ Publication No. 12- E005-EF*. Rockville, MD: Agency for Healthcare Research and Quality (US); 2012.

6. Centers for Medicare & Medicaid Services. EHR Incentive Programs. Available at: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/ehrincentiveprograms/. Accessed May 5, 2013.

7. Office of the National Coordinator for Health Information Technology. Step 5: Achieve Meaningful Use Stage 2 | Providers & Professionals | HealthIT.gov. Available at: http://www.healthit.gov/providers-professionals/step-5-achieve-meaningful-use-stage-2. Accessed May 10, 2014.

8. Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. *Health Aff (Millwood)*. 2005;24(5):1290–5. doi:10.1377/hlthaff.24.5.1290.

9. Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood)*. 2009;28(2):323–33. doi:10.1377/hlthaff.28.2.323.

10. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)*. 2010;29(7):1370–5. doi:10.1377/hlthaff.2010.0048.

11. Liederman EM, Lee JC, Baquero VH, Seites PG. The impact of patient-physician Web messaging on provider productivity. *J Healthc Inf Manag*. 2005;19(2):81–6.

12. Zickmund SL, Hess R, Bryce CL, et al. Interest in the use of computerized patient portals: role of the provider-patient relationship. *J Gen Intern Med*. 2008;23 Suppl 1:20–6. doi:10.1007/s11606-007-0273-6.

13. Wagner PJ, Dias J, Howard S, et al. Personal health records and hypertension control: a randomized trial. *J Am Med Inform Assoc*. 2012;19(4):626–34. doi:10.1136/amiajnl-2011-000349.

14. Gysels M, Richardson A, Higginson IJ. Does the patient-held record improve continuity and related outcomes in cancer care: a systematic review. *Health Expect*. 2007;10(1):75–91. doi:10.1111/j.1369-7625.2006.00415.x.

15. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc*. 2006;13(2):121–6. doi:10.1197/jamia.M2025.

16. Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). *J Am Med Inform Assoc*. 2008;15(6):729–36. doi:10.1197/jamia.M2547.

17. Wilson C, Peterson A. *Managing Personal Health Information: An Action Agenda. (Prepared by Insight Policy Research under Contract No. HHSA290200710072T.) AHRQ Publication No. 10-0048-EF.* Rockville, MD; 2010.

18. Hibbard JH, Greene J. Who are we reaching through the patient portal: engaging the already engaged? *Int J Pers Cent Med*. 2011;1(4):788–93.

19. Winkelman WJ, Leonard KJ, Rossos PG. Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *J Am Med Inform Assoc*. 2004;12(3):306–14. doi:10.1197/jamia.M1712.

20. Weiner JP. Doctor-patient communication in the e-health era. *Isr J Health Policy Res*. 2012;1(1):33. doi:10.1186/2045-4015-1-33.

21. Agarwal R, Anderson C, Zarate J, Ward C. If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging. *J Med Internet Res*. 2013;15(2):e43. doi:10.2196/jmir.2243.

22. Van Weert JCM, Bolle S, van Dulmen S, Jansen J. Older cancer patients' information and communication needs: What they want is what they get? *Patient Educ Couns*. 2013;92(3):388–97. doi:10.1016/j.pec.2013.03.011.

23. Clauser SB, Wagner EH, Aiello Bowles EJ, Tuzzio L, Greene SM. Improving modern cancer care through information technology. *Am J Prev Med*. 2011;40(5 Suppl 2):S198–207. doi:10.1016/j.amepre.2011.01.014.

24. Dollinger M. Guidelines for Hospitalization for Chemotherapy. *Oncologist*. 1996;1(1 & 2):107–111.

25. Knowles G, Tierney A, Jodrell D, Cull A. The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer. *Eur J Oncol Nurs*. 1999;3(4):208–220. doi:10.1016/S1462-3889(99)81332-5.

26. Wiljer D, Leonard KJ, Urowitz S, et al. The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients. *BMC Med Inform Decis Mak*. 2010;10:46. doi:10.1186/1472-6947-10-46.

27. Husson O, Mols F, van de Poll-Franse L V. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol*. 2011;22(4):761–72. doi:10.1093/annonc/mdq413.

28. Ruland CM, Andersen T, Jeneson A, et al. Effects of an internet support system to assist cancer patients in reducing symptom distress: a randomized controlled trial. *Cancer Nurs*. 2013;36(1):6–17. doi:10.1097/NCC.0b013e31824d90d4.

29. Ong LM, Visser MR, van Zuuren FJ, Rietbroek RC, Lammes FB, de Haes JC. Cancer patients' coping styles and doctor-patient communication. *Psychooncology*. 1999;8(2):155–66. doi:10.1002/(SICI)1099-1611(199903/04)8:2<155::AID-PON350>3.0.CO;2-A.

30. Unruh KT, Pratt W. Barriers to organizing information during cancer care: "I don't know how people do it.". *AMIA Annu Symp Proc*. 2008:742–6.

31. Miller R. Web portals and patient information-seeking behaviors. *J Oncol Pract*. 2009;5(4):182–3. doi:10.1200/JOP.0941506.

32. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns*. 2005;57(3):250–61. doi:10.1016/j.pec.2004.06.006.

33. Ruland CM, Maffei RM, Børøsund E, Krahn A, Andersen T, Grimsbø GH. Evaluation of different features of an eHealth application for personalized illness management support: Cancer patients' use and appraisal of usefulness. *Int J Med Inform*. 2013;82(7):593–603. doi:10.1016/j.ijmedinf.2013.02.007.

34. Van Mossel C, Leitz L, Scott S, et al. Information needs across the colorectal cancer care continuum: scoping the literature. *Eur J Cancer Care (Engl)*. 2012;21(3):296–320. doi:10.1111/j.1365-2354.2012.01340.x.

35. American Cancer Society. Colorectal Cancer Facts & Figures 2011-2013. 2011. Available at: http://www.cancer.org/research/cancerfactsstatistics/colorectal-cancer-facts-figures.

36. American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2012-2013. 2012. Available at: http://www.cancer.org/Research/CancerFactsStatistics/cancer-treatment-survivorship-facts-figures.pdf.

37. Jonker DJ, Spithoff K, Maroun J. Adjuvant systemic chemotherapy for Stage II and III colon cancer after complete resection: an updated practice guideline. *Clin Oncol (R Coll Radiol)*. 2011;23(5):314–22. doi:10.1016/j.clon.2011.02.010.

38. Chang GJ, Kaiser AM, Mills S, Rafferty JF, Buie WD. Practice parameters for the management of colon cancer. *Dis Colon Rectum*. 2012;55(8):831–43. doi:10.1097/DCR.0b013e3182567e13.

39. Johns Hopkins Medicine. Epic at Johns Hopkins Medicine - MyChart. Available at: http://www.hopkinsmedicine.org/epic/manager_toolkit/my_chart_overview.html. Accessed October 30, 2013.

40. Carayon P, Schoofs Hundt A, Karsh B-T, et al. Work system design for patient safety: the SEIPS model. *Qual Saf Health Care*. 2006;15 Suppl 1:i50–8. doi:10.1136/qshc.2005.015842.

41. Unruh KT, Pratt W. The Invisible Work of Being a Patient and Implications for Health Care: "[the doctor is] my business partner in the most important business in my life, staying alive." *Conf Proc Ethnogr Prax Ind Conf*. 2008;2008(1):40–50. doi:10.1111/j.1559-8918.2008.tb00093.x.

42. Holden RJ, Carayon P, Gurses AP, et al. SEIPS 2.0: a human factors framework for studying and improving the work of healthcare professionals and patients. *Ergonomics*. 2013:1–18. doi:10.1080/00140139.2013.838643.

43. Holden RJ, Mickelson RS. Performance barriers among elderly chronic heart failure patients: An application of patient-engaged human factors and ergonomics. *Proc Hum Factors Ergon Soc Annu Meet*. 2013;57(1):758–762. doi:10.1177/1541931213571166.

44. Crabtree B, Miller W. *Doing Qualitative Research*. 2nd ed. (Crabtree B, Miller W, eds.). Newbury Park, CA: Sage Publications; 1999.

45. Rowan M, Huston P. Qualitative research articles: information for authors and peer reviewers. *CMAJ*. 1997;157(10):1442–6.

46. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–88. doi:10.1177/1049732305276687.

47. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107–15. doi:10.1111/j.1365-2648.2007.04569.x.

48. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105–12. doi:10.1016/j.nedt.2003.10.001.

49. Namey E, Guest G, Thairu L, Johnson L. Data reduction techniques for large qualitative data sets. In: Guest G, MacQueen KM, eds. *Handbook for team-based qualitative research*. Lanham: Rowman Altamira; 2008:137–161.

50. Johns Hopkins Medicine. MyChart Tips and Tricks. Available at: http://restricted.hopkinsmedicine.org/epic/training/myc_tt.html. Accessed October 1, 2014.

51. Van de Castle B, Wilt M, Takatori K. *Finding Meaningful Use in Patient Portals*. Anaheim, CA; 2014.

52. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer*. 1995;76(2):167–77.

53. Groll RJ, Leonard KJ, Eakin J, Warde P, Bender J, Jewett MAS. Electronic surveillance of testicular cancer: understanding patient perspectives on access to electronic medical records. *J Oncol Pract*. 2009;5(4):177–81. doi:10.1200/JOP.0942004.

54. Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nurs*. 2009;32(1):11–23; quiz 24–5. doi:10.1097/01.NCC.0000343372.24517.bd.

55. Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: part 2: understanding patterns of information disinterest and avoidance. *Cancer Nurs*. 2009;32(1):26–36. doi:10.1097/01.NCC.0000343373.01646.91.

56. McCaughan E, McKenna H. Never-ending making sense: towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients. *J Clin Nurs*. 2007;16(11):2096–104. doi:10.1111/j.1365-2702.2006.01817.x.

Appendices

Appendix 1: Initial Interview Guide

Patients (with MyChart account):

1. Please describe what you do to prepare for your chemotherapy appointment
    a. What information is used
    b. What technology/tools are used
    c. Has this changed over time
2. What/Who has been helpful during these processes?
    a. Who takes care of you at home? What do they do for you (how do you decide on the roles)?
3. When you needed to know something, what did you do? Where did you go to for that information? (E.g. questions about instructions given to you, question about lab results, information about potential side effects or ones you are experiencing)
    a. When you have questions for your provider, what do you do? What have you been told to do?
    b. If you experience side effects, what do you do? What have you been told to do?
4. Was there a time when you were not able to find the information you needed? What difficulty have you experienced while looking for the information you needed?
5. Please describe your prior level of experience with computer and internet use
6. Have you heard about the patient's electronic health record/patient portal, which is called MyChart? Have you used it?
    a. If yes: What do you use it for most often?
    b. If no: Why not?

Additional question for patients without MyChart account:

7. Have you heard about the patient's electronic health record/patient portal, which is called MyChart?
    a. If you had the ability to send a secure email to your provider, would you have done that in those above situations?
    b. If you haven't had those problems/situations, what do you think about that option?

Healthcare professionals:

1. What kinds of questions do you get from patients when they are home after a chemotherapy session? How do they contact you?
2. What recommendations have you made to your patients about when and how to contact the providers if they have questions? If they are experiencing side effects?
3. Have you ever experienced any difficulty while coordinating care with patients during their interim period (in between clinic visits)?
    a. What do you do when you experience this difficulty?
    b. How do you think the system/workflow can be fixed to reduce that difficulty?
4. What do you think the patients' information needs are when they deal with the complex processes of chemotherapy treatment?
5. Have you talked to your patients about MyChart?
6. Do you use In Basket in EPIC to answer patient messages? How do you designate who takes the message from patients' MyChart?

Appendix 2: Revised Interview Guides

NOTE: This is for Patient Interviews

General

1. Please tell me your age.
2. Please describe what you usually do to prepare for your chemotherapy appointment.
    a. Has this changed over time?
3. When was your last chemo session (appointment)?

Information needs & communication methods

4. During that time (between last chemo and today), did you have any questions or concerns?
    a. Could you describe what they were?
    b. Did you reach out to anyone or try to find information about it from home?
        i. (If reach out with email or phone) What types of questions do you use email for? Phone for? Why?
        ii. (If waited until face-to-face encounter) What made you decide to wait until the encounter/appointment?
        iii. (If search for information in general) What information source do you go to? Why?
    c. Were you able to resolve questions/concerns? If yes, how? If not, why?
    d. How about other times when you were home in between your chemo appointments?
5. When you experience side effects at home, what do you do?
    a. What have you been told to do?
6. Was there a time when you were not able to find the information you needed? What difficulty have you experienced while looking for the information you needed?

Information provisioning prior to start of chemo

7. Do you think you were well prepared (know what to expect) before you started chemo?
    a. If yes, what helped you become prepared?
        i. Have you ever experienced anything that was unexpected?
            1. If yes, how did you resolve it?
    b. If not, has anyone or any tool been helpful since?
    c. Have you received the yellow Patient Guide binder at the chemo class? Do you use it?

MyChart

8. Have you heard about the patient's electronic health record/patient portal, which is called MyChart? Have you used it?
    a. If yes:
        i. What do you use it for most often?
        ii. What about it that made you sign up for MyChart?
    b. If no:
        i. Why not?
        ii. If you had the ability to send a secure email to your provider, would you have done that when you had questions or concerns at home?

Appendix 2: Revised Interview Guides (continued)

NOTE: This is for Physician and Infusion Center Nurse Interviews

Intro: My understanding is that colorectal patients regimen requires them to come in for chemo once in every two weeks or so

Questions outside clinic:

- In between those chemo session, have you ever been contacted by your colorectal patients with questions or concerns?
    - Examples of questions or concerns
- How do they contact you?
- What recommendations have you made to your patients about contacting their providers when they have questions or concerns?

MyChart & InBasket:

- Have you talked to your patients about MyChart?
- What do you tell them about MyChart? Do you emphasize any specific function or module of MyChart?
- Have you ever used the InBasket to answer patient messages?
    - If yes: Pool – have you discussed with your pool members who takes what message?
    - If no: Why not? What do you think about the option of patients contacting you through MyChart messages?

- How do you want the patients to use MyChart so that it will help both the patients and your work of caring for these patients?

- In terms of workflow, have you ever experienced any difficulty coordinating care when your patient contacts you with questions or concerns?

(Optional question for nurses: Do you work in the triage?)

- *If yes, refer to triage interview guide*

Questions at clinic:

- What kinds of questions do you get from patients when they come in?
- Are there any concerns or questions that you hear more from colorectal cancer patients compared to other patients, like pancreatic or gastric?

General perception of patient information need:

- *What do you think the patients' information needs are when they deal with chemotherapy treatment?*

Appendix 2: Revised Interview Guides (continued)

NOTE: This is for Triage Nurse Interviews

Questions from patients:

- Could you describe a typical call you receive from patients?
- Have you ever received calls from colorectal cancer patients?
    - What questions or concerns or requests did they have?
- What kind of calls are "non triage calls"?

Documentation:

- Could you describe to me how you document patient calls?

Internal Communication:

- Who do you notify about the calls? (Physicians only?)
- How do you notify them?
    - Do you use the Outlook, Page/Ping, or call them?
- Do you notify in Epic?
    - If so, do you use the Pool?

Appendix 3: Patient Recruitment Flyer

We are conducting a research study on understanding how technology could assist colorectal cancer patients in information management.
We need your help.

Study purpose:
To understand how colorectal cancer patients and their providers currently manage information outside the clinic and how patient portals could be used to aid this process.

Study procedure:
We would like to request your time for either an in-person or phone interview that will last about 15-20 minutes. During the interview we will ask about what you do to prepare for your chemotherapy appointment, the types of information you need at home when managing your treatment, your preferred source of information, and your experience with the new patient portal called "MyChart". The interview will be audio recorded. You do not have to answer any question you do not want to answer.

Contact Information:
If you are interested in joining or have any questions about the study (Study Number: NA_00089889), please contact:

Koko Takatori
Phone: 347-510-4091
Email: ktakato1@jhmi.edu

OR

Dr. Ayse P. Gurses, Principal Investigator
Phone: 410-614-1876
Email: agurses1@jhmi.edu

Appendix 4: HCP Recruitment Email Script

Dear (name of provider):

Hello, my name is Koko Takatori, a second-year graduate student at School of Medicine, Division of Health Sciences Informatics. I am a member of a research team and contacting you to request your time for an interview that will last about 15-20 minutes. The interview could be done in person or over the phone.

The purpose of the research study is to understand how colorectal cancer patients and their providers currently manage the patient's chemotherapy treatment outside the clinic and how Epic's patient portal ("MyChart") could be used to aid this process. You are being asked to participate because you are in a care provider role for colorectal cancer patients receiving chemotherapy treatment, and your input will be very valuable.

During the interview, we will ask about the types of question you receive from patients when they are home and how they contact you, your preference on when and how patients should contact you, whether you have experienced any difficulty coordinating care with patients between their clinic visits, and your prior experience with handling patients' MyChart messages. The interview will be audio recorded. You do not have to answer any question you do not want to answer.

We will not collect any identifiable personal information in any part of the research study. Information obtained from you will only be reported in aggregate. You will have the option of withdrawing from the study at any time during and immediately after the interview. A more detailed description of the study could be found in the copy of the oral consent script attached to this email.

If you are interested in participating, please let me know the best time and number to reach you and talk about the research study. If you have any questions, please do not hesitate to contact me (Phone: 347-510-4091, Email: ktakato1@jhmi.edu) or the Principal Investigator, Dr. Ayse P. Gurses (Phone: 410-614-1876, Email: agurses1@jhmi.edu).

Thank you very much for your time.

Sincerely,
Koko Takatori
M.S. Research Candidate '14
Division of Health Sciences Informatics
Johns Hopkins School of Medicine
ktakato1@jhmi.edu
(347) 510-4091

Appendix 5: Oral Consent Form Scripts

ORAL CONSENT SCRIPT

(for patient interviews)

You are being asked to take part in a research study. I am a member of the research team and contacting you to request your time for an in-person interview that will last about 15 to 20 minutes. The purpose of this study is to understand how colorectal cancer patients and their providers manage the patient's chemotherapy treatment and side effects outside the clinic and the role of MyChart in this process.

We know that the diagnosis of cancer causes a significant increase in the responsibility of patients and their family members to manage their disease and treatment at home. As you may have already heard, MyChart is a web-based patient portal with tools that may assist patients and their family members in their health information management and securely communicate with their providers at the convenience of their homes. For MyChart to better serve the needs of colorectal cancer patients in outpatient chemotherapy, we want to understand what information patients need at home to manage their chemotherapy treatment (for example, preparing for upcoming chemotherapy sessions, managing treatment side effects at home, and so forth) and the processes currently used to meet these needs. We also want to compare the perspectives of patient and provider preferences (for example, preferred source of information and communication methods for certain types of information) to better understand what the role of MyChart should be in their current care setting.

You are being asked to participate because you are currently receiving chemotherapy treatment for colorectal cancer, and your input during the interview will be very valuable. If you agree to be in this study, we will interview you once. All conversations will be recorded using a digital voice recorder and then transcribed. During the interview, you will be asked about what information and tools have been useful to you in preparing for your chemotherapy appointments, whether you have experienced any difficulty while seeking information, and your prior experience with MyChart. The interview could take place here today or scheduled for a later time or done over the phone.

To understand the portal usage patterns by different demographic groups, we will also ask for your age, sex, race/ethnicity, and MyChart sign-up status (in other words, whether or not you have activated your MyChart account) during the interview, but we will not collect any information that is identifiable (such as your name, address, social security number, medical record number, or any account numbers and user names including MyChart). If any individually identifiable information is discussed during the interview, the researcher will erase that portion of the voice record immediately after the interview is complete. The voice recording of the interview will be destroyed within 2 weeks following the interview. People at Johns Hopkins who are involved in the study or who need to make sure the study is being done correctly will see the information. Only those people directly involved in the research will handle your information. Your information will always be grouped with the information from other patients when analyzed, and you will not be identified by name in any analysis.

We believe participating in this study has very little risk to you. You may get tired or bored when we are asking you questions. You do not have to answer any question you do not want to answer.

There is no direct benefit to you for participating in the study. However, this study may benefit the society by suggesting an effective use case of patient portals to improve quality of care and collaboration between colorectal cancer patients undergoing chemotherapy and their providers.

You will have the option of withdrawing from the study at any time during and immediately after the interview. In such a case, we will erase all the data collected from you by destroying the digital voice record. If you decide to withdraw from the study, you will not incur any penalties or loss of benefits that you would have otherwise been entitled to. Please note that it will not be possible for you to withdraw from the study after the interviews are transcribed and combined with the previously collected data. This is because all the data collection is anonymous and we are not collecting any personal identifiers that can be used to track down the particular interview.

People at Johns Hopkins may need to send your information to people outside of Johns Hopkins (for example, government groups like the Food and Drug Administration) who need to make sure the study is being done correctly. These people will use your information for the purpose of the study.

We will continue to collect information about you until the end of the study unless you tell us that you have changed your mind. If you change your mind and don't want your information used for the study anymore, you can call The Johns Hopkins Institutional Review Board at 410-955-3008. Just remember, if we have already used your information for the study, the use of that information cannot be cancelled. We try to make sure that everyone who needs to see your information uses it only for the study and keeps it confidential - but, we cannot guarantee this.

You do not have to agree to be in this study. If you do not want to join the study, it will not affect your care at Johns Hopkins in any way. If you have any questions about your rights as a research participant, or if you think you have not been treated fairly, you may call the Johns Hopkins Institutional Review Board (IRB) at 410-955-3008.

You may ask any questions about the study now, or if you have questions about the study later, you are encouraged to contact Dr. Ayse P. Gurses (Phone: 410-614-1876, Email: agurses1@jhmi.edu).

Appendix 5: Oral Consent Form Scripts (continued)

ORAL CONSENT SCRIPT

(for provider interviews)

You are being asked to take part in a research study. I am a member of the research team and contacting you to request your time for an in-person interview that will last about 15 to 20 minutes. The purpose of this study is to understand how colorectal cancer patients and their providers manage the patient's chemotherapy treatment and side effects outside the clinic and the role of MyChart in this process.

We know that the diagnosis of cancer causes a significant increase in the responsibility of patients and their family members to manage their disease and treatment at home. As you may know, MyChart is a web-based patient portal with tools that may assist patients and their family members in their health information management and securely communicate with their providers at the convenience of their homes. For MyChart to better serve the needs of colorectal cancer patients in outpatient chemotherapy, we want to understand what information patients need at home to manage their chemotherapy treatment (for example, preparing for upcoming chemotherapy sessions, managing treatment side effects at home, and so forth) and the processes currently used to meet these needs. We also want to compare the perspectives of patient and provider preferences (for example, preferred source of information and communication methods for certain types of information) to better understand what the role of MyChart should be in their current care setting.

You are being asked to participate because you are in a care provider role for colorectal cancer patients receiving chemotherapy treatment, and your input during the interview will be very valuable. If you agree to be in this study, we will interview you once. All conversations will be recorded using a digital voice recorder and then transcribed. During the interview, you will be asked about your perception of patients' information needs that arise at patients' homes, your preferences on information sources and communication methods used by patients when they are home, whether you have experienced any difficulty coordinating care with patients between their clinic visits, and your prior experience with handling patients' MyChart messages. The interview can take place at a private location and time most convenient for you or done over the phone.

We will not collect any identifiable information about you or patients. If any individually identifiable information is discussed during the interview, the researcher will erase that portion of the voice record immediately after the interview is complete. The voice recording of the interview will be destroyed within 2 weeks following the interview. People at Johns Hopkins who are involved in the study or who need to make sure the study is being done correctly will see the information. Only those people directly involved in the research will handle your information. Your information will always be grouped with the information from other patients when analyzed, and you will not be identified by name in any analysis.

We believe participating in this study has very little risk to you. You may get tired or bored when we are asking you questions. You do not have to answer any question you do not want to answer.

There is no direct benefit to you for participating in the study. However, this study may benefit the society by suggesting an effective use case of patient portals to improve quality of care and collaboration between colorectal cancer patients undergoing chemotherapy and their providers.

You will have the option of withdrawing from the study at any time during and immediately after the interview. In such a case, we will erase all the data collected from you by destroying the digital voice record. If you decide to withdraw from the study, you will not incur any penalties or loss of benefits that you would have otherwise been entitled to. Please note that it will not be possible for you to withdraw from the study after the interviews are transcribed and combined with the previously collected data. This is because all the data collection is anonymous and we are not collecting any personal identifiers that can be used to track down the particular interview.

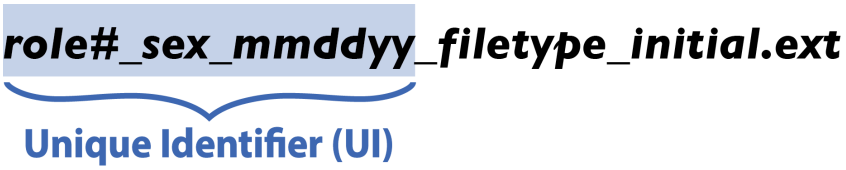
People at Johns Hopkins may need to send your information to people outside of Johns Hopkins (for example, government groups like the Food and Drug Administration) who need to make sure the study is being done correctly. These people will use your information for the purpose of the study.

We will continue to collect information about you until the end of the study unless you tell us that you have changed your mind. If you change your mind and don't want your information used for the study anymore, you can call The Johns Hopkins Institutional Review Board at 410-955-3008. Just remember, if we have already used your information for the study, the use of that information cannot be cancelled. We try to make sure that everyone who needs to see your information uses it only for the study and keeps it confidential - but, we cannot guarantee this.

You do not have to agree to be in this study. If you do not want to join the study, it will not affect your employment in any way. If you have any questions about your rights as a research participant, or if you think you have not been treated fairly, you may call the Johns Hopkins Institutional Review Board (IRB) at 410-955-3008.

You may ask any questions about the study now, or if you have questions about the study later, you are encouraged to contact Dr. Ayse P. Gurses (Phone: 410-614-1876, Email: agurses1@jhmi.edu).

Appendix 6: File Naming Convention



Section of a file name	Attribute (Description)
role	pt (patient)
	n (nurse)
	t (triage)
	d (doctor)
#	(*n*-th interviewee in that role)
sex	f (female)
	m (male)
mmddyy	(month, date, year of the interview)
filetype	int (interview recording)
	tx (transcript)
initial	(researcher initials)
.ext	(file extension)

e.g. "pt09_m_032714_tx_KT.docx" is a transcript by researcher KT of an interview that took place on March 27, 2014 with a male patient, who was the 9th patient interviewee.

Appendix 7: Code Frequencies in Patient Transcripts

Code Name	# Res.	# Mention
pt_P_CareCoord	**9**	**21**
Scheduling Next Appointment	7	12
Obtaining refilled Rx	3	3
Liaising btwn Chemo Team and Others	3	6
pt_P_Communication	**9**	**56**
General Process of Communicating with HCPs	7	26
Question or Update on Symptoms or HomeProcedures	6	18
Question or Update on PHI	5	8
Q or U on Ext Info or Non-Clinical to keep everydaylife	3	4
pt_P_SelfManage	**10**	**209**
Seek Manage External Info	10	38
(MC) PHI Management	10	33
Socio-emotional Well-being	10	33
T-PreChemo Visit Prep	10	18
Everyday life-patient life Balance	9	19
(MC) Tracking Appointments	8	14
Symptom Management	8	30
T-First Chemo Prep	7	10
T-PostChemo Visit	6	14
pt_Work System	**10**	**901**
pt_Person	**10**	**452**
InfoNeeds	**10**	**188**
Symptoms Experienced	**9**	**53**
Need personalized info for expected symptoms and prognosis, not general	**8**	**19**
Being upset from general info on disease and med	7	9
Emotionally hard to seek other pt info	2	2
Annoyed at HCPs for not having personalized answer	1	2
Value autonomy, sense of having of control	**8**	**24**
Wanting to be aware of what's going on	4	7
Sense of privacy	1	1
Being upset from not being organized	1	1
Emotionally upset from uncertainty re symptom or change in physical state	**8**	**22**
Being always worried, anxious	3	5
Emotionally hard to face metastatic and recurrent cancer	2	3
Knowledge based on personal experience	**7**	**11**
Reassured by HCP Advice	**6**	**15**

Appendix 7: Code Frequencies in Patient Transcripts (continued)

Minimum necessary information	**6**	**9**
I know what scares me	4	4
Hope of being cured	**5**	**13**
Not interested in the history	1	1
Unable to do what you used to do due to symptom	**4**	**11**
Don't want to disturb busy HCPs	**4**	**5**
Need to get away from chemo	**4**	**29**
Not being yourself after chemo	3	5
Sense of being poisoned	3	5
Sense of resignation	2	3
Willing to try anything new	2	5
Mistrust in US methods, comparing with Europe	2	4
Getting tired of treating cancer, not as easy as it was	1	1
Prefer passive role in Tx decision making	**4**	**9**
HCPs have access to more info resource	2	3
Don't want to think about cancer all the time	**3**	**6**
Difficulty finding info relevant to their circumstance	**3**	**9**
deep into Tx, can only find basic info	2	3
Exeripencing unusual side effects	2	4
Being upset, unable to find info	2	2
Being upset from test results	**3**	**4**
Other pt exp with Alt Tx, ways to manage unusual symptom	**3**	**5**
Depressed, feeling alone	**2**	**7**
Difficulty describing toughness of chemo to non-patients	1	3
Ways to cut down perceived time of infusion	**2**	**2**
Experience different side effects from wk to wk	**2**	**7**
Difficulty sleeping the night before Tx	1	2
Anxiety from not knowing what side effect to expect	1	1
Reassured by other source	**1**	**2**
Been thru, strategy change over time	**1**	**1**
Depressed, too sick to argue	**1**	**1**
pt_Task	**10**	**175**
Tracking test results (general)	**9**	**25**
Tracking CEA	4	6
Understanding what the test results mean	3	4
Communicate concern re PHI to HCP	2	3
Making sure appointment is scheduled	**7**	**12**
Checking MyChart for new appointment	4	6

Appendix 7: Code Frequencies in Patient Transcripts (continued)

Messaging HCP to check schedule	3	3
Calling in to check appointment	2	2
Receive call and document re new appointment	1	1
Keeping work-life-Tx balance	**7**	**22**
Taking care of other family members	4	5
Preparing for side effects, planning around it	4	8
Getting household work done	3	5
Home care procedures	**7**	**20**
Taking medication	4	7
Managing infusion pump at home	2	4
De-accessing the port	2	2
Managing ostomy bag	2	5
Preparing the port	2	2
Making sure to eat and drink fluid	**6**	**10**
Transportation to and from clinic or lab	**6**	**7**
Prepare a bag of necessary goods to bring in for visit	**5**	**6**
Don't do external research	**5**	**7**
Keeping track of meds, request refill	**5**	**5**
Go through HCP-provided ed material	**5**	**7**
Research AltTx information	**4**	**10**
Financial work	**4**	**4**
Getting hold of HCPs	**4**	**9**
Getting tests done	**3**	**5**
Getting blood test done early save time	2	3
Organizing, sharing PHI with others	**3**	**5**
Get good night's sleep day before Tx	**2**	**2**
Prepare for doc visit	**2**	**2**
Seek other pt opinion and experiences	**2**	**2**
Managing appearance	**2**	**5**
Trying to keep up with multiple tasks	**2**	**3**
Don't look at scan reports	**2**	**2**
Figure out next scan appt	**2**	**2**
Req appt, receive follow up to req	**1**	**1**
Wait and see reaction to chemo	**1**	**2**
pt_Organization	**10**	**125**
Pt-Fam_Teamwork	**10**	**66**
Non-clinical management by family	6	8
Not (or won't or can't) rely on others	5	10
Info management by family	5	17

Appendix 7: Code Frequencies in Patient Transcripts (continued)

Emotional support by family	4	5
Discussion of roles	4	4
Only rely on close family member	3	3
Clinical management by family	3	7
Backup support by family	3	3
CareCoord by family	2	3
Comm with HCP by family	2	6
Degree of side effect determine contacting HCP	**7**	**9**
pt-HCP_LogisticalAdvice	**7**	**12**
HCP action encouraging email	5	6
Call for symptom management	2	3
Using outside labs	1	1
Use email, not MC msg	1	2
Pt-HCP_ClinicalAdvice	**7**	**16**
No particular routine for chemo prep	**5**	**5**
Pt-HCP team work, common knowledge	**3**	**3**
Pt-HCP_TalkAboutMC	**3**	**4**
HCP not clarifying where to find activation code	1	1
HCP telling pt they use MyChart	1	1
MC msg doesn't work well	1	2
Clinical management by homecare nurse	**3**	**3**
Do everything by schedule, routine	**2**	**4**
one-on-one relationship with HCPs	**2**	**2**
Pt-HCP_PHIManageStrat	**1**	**1**
pt_ToolsTech	**10**	**149**
MyChartFacilitator	**9**	**43**
Tracking PHI and Appointment	9	21
Email reminders and notifications	4	4
Getting hold of HCPs (esp NP, RN) that you don't have direct contact info	3	9
Portability of data	3	7
Schedule Appt thru MC easier than phone	2	2
Primary info source - HCPs	**9**	**25**
For having personally relevant answer or info	6	7
For their expertise and resources available to them	4	5
To avoid being upset from external info or trying to figure out what the PHI means	4	5
Generic or irrelevant info sources are not helpful	4	8

Appendix 7: Code Frequencies in Patient Transcripts (continued)

Primary Communication tool - Email	**8**	**30**
Email - Direct contact with HCPs with reasonable turn around time	6	13
Phones - Bad response or inefficiencies	4	6
Phone for emergency. Otherwise, email.	3	6
Phone when email turn around time is slow	2	4
Email - ability to store info to check later	1	1
Use of internet as info source	**8**	**15**
For alternative treatment info	4	5
For general disease med info	4	4
For other pt experience info	3	3
For symptom management info	3	3
MyChartBarrier	**7**	**15**
Email is easier, works better and more personal	5	7
Unclear how to sign up	2	3
Offers access to unnecessary PHI	2	3
Test release slow	1	2
Serendipitous info sources used	**4**	**5**
Reputable info source used	**3**	**4**
Reasons family using tech for pts	**3**	**7**
PHI organizer - print outs in physical folder	**3**	**5**

Appendix 8: Code Frequencies in HCP Transcripts

Code Name	# Res	# Mention
HCP_P_HCP-Pt Communication and Coordination	**10**	**136**
HCP_P_Triage call	**10**	**54**
HCP_P_Internal Communication and Coordination	**10**	**82**
InternalComm	10	51
TeamMentalModel	8	17
PoolDiscussion	5	5
HCP_P_GeneralChemoVisit	**9**	**28**
HCP_P_Lab release	5	13
HCP_P_First visit	3	4
HCP_P_Appt notice to pt	2	7
HCP_Work System	**10**	**615**
HCP_Organization	**10**	**195**
HCP_Teamwork	**10**	**73**
InternalComm	10	51
TeamMentalModel	8	17
PoolDiscussion	5	5
HCP_ExComm_Out	**10**	**71**
LogisticalAdviceOrInfo	9	31
TalkAboutMC	8	19
ClinicalAdviseOrInfo	7	18
PHIManageStrategy	2	2
ExInfoSourceAdvice	1	1
HCP_ExComm_In	**8**	**40**
Triage	5	13
Email	5	8
MyChartMessage	4	11
StationPhone	4	6
PhysicianPhone	2	2
HCP_OrgCulture	**6**	**11**
HCP_Person	**10**	**232**
HCP_PercPtInfoNeeds	**10**	**129**
HCP_IndPracticeVar	**10**	**46**
GiveOutPersonalContact	7	10
DirectPtCare	5	11

Appendix 8: Code Frequencies in HCP Transcripts (continued)

ProactivePtCare	3	7
UseStationPhone	3	3
TriageIndPracVar	3	8
TellPtAbtMyChart	2	2
TurnAroundTime	2	2
CommCaregiver	1	1
OffHourResponse	1	1
DocumentEmailConvo	1	1
HCPPercPtPsychosocial issues	**8**	**34**
IndInfoNeedVar	2	3
Don'tWantToDisturb	1	1
HCPPercPtProbWithCompliance	**6**	**13**
HCP_PercCaregiverNeeds	**3**	**7**
PersonalExperience	**3**	**3**
HCP_Task	**10**	**71**
JobAmbiguity	**6**	**14**
JobDemands	**6**	**30**
JobAutonomy	**5**	**7**
TriageInfoNeed	**3**	**20**
HCP_ToolTech	**10**	**116**
HCP_MCBarrierProbs	**7**	**34**
HCP_Uncertain_Wrong	6	14
HCP_PercPtMCFacilitator	**7**	**26**
HCP_PercPtMCBarrier	**7**	**23**
HCP_InBasBarrierProbs	**5**	**25**
HCP_MCFacilitator	**2**	**8**
HCP_Environment	**1**	**1**

Appendix 9: HCP Codebook

SEIPS Component	Subcategory (Parent node)	Subcategory (Child node, if any)
Processes	*HCP_P_HCP-Pt Communication and Coordination*: Aspects of HCP-Patient communication and coordination e.g. Actual and preferred communication methods for certain inquiries	
	HCP_P_Internal Communication and Coordination: Aspects of HCP-only (i.e. Physician, Nurse, and Triage) teamwork e.g. Shared mental model; e.g. Communication methods	
	HCP_P_Triage call: Process or workflow regarding triage calls	
	HCP_P_GeneralChemoVisit: Process or workflows related to chemotherapy visit	HCP_P_Lab release: Process, workflow, timing of how labs (e.g. blood work, scan reports) are released to patients, including in-person as well as on MyChart (if patient is signed up)
		HCP_P_First visit: Process or workflow to accommodate patients during/after their first visit e.g. 1-on-1 chemo class with their nurses; discussion of communication methods and off-hour resources
		HCP_P_Appt notice to pt: Process or workflow where patients find out about their next appointment
Organization	*HCP_ExComm_In:* INCOMING Communication from Patients to HCPs (e.g. provider perception of	Email MyChartMessage

	which tool is used by patient for what purpose)	PhysicianPhone StationPhone Triage
	HCP_ExComm_Out: OUTGOING Communication from HCPs to patients in terms of guidance on process; what HCPs tell the patients to do. (e.g. which tools to use for what purpose; e.g. how to manage side effects)	ClinicalAdviseOrInfo: Clinical advise/content/information that HCPs explicitly tell/give patients. does NOT include which communication method to use for what - that goes into Logistical. (e.g. information on treatment, side effects, symptom management, etc.) ExInfoSourceAdvice: HCP advice to patients about external information sources (e.g. where official sites are for clinical trials) LogisticalAdviceOrInfo: what HCPs tell/contact patients about (1) how to contact HCPs with questions/concerns (e.g. "proper" (or at times "preferred") channel of communication); e.g. jot down questions for next face-to-face meeting); PHIManageStrategy: what HCPs tell patients about how to organize/manage their Personal Health Information (PHI) for what purpose. does NOT include how to manage PHI using MyChart - that goes into TalkAboutMC (e.g. keep a diary at home for MD visit; e.g. keep lab result copies in a folder to see trend) TalkAboutMC: What providers explicitly tell patients about MyChart; (e.g. what module is emphasized; e.g. recommendations they make about how MyChart could be used; e.g. steering patients to MyChart from email)

	HCP_OrgCulture: Organizational culture, tradition, how something used to be (or are being) done that is not based on organizational policy, evidence, or patient preference.	
	HCP_Teamwork: Aspects of HCP-only (i.e. Physician, Nurse, and Triage) teamwork; (e.g. Shared mental model; e.g. Communication methods)	InternalComm: Internal communication among HCPs, especially challenges faced while using InBasket (e.g. problems with Pool when dealing with Triage Calls and MyChart messages); includes any mention of pool discussion; PoolDiscussion: Communication among care team members on pool responsibilities TeamMentalModel: Any mention of HCPs' shared (or not) understanding of role and functions of each team member, task requirements and the coordination activities required for providing pt care.
Person	*HCP_IndPracticeVar:* Individual Practice Variation. Differences among individual care providers within the same institution in performing tasks and procedures in ways that are driven by habits, experience or preferences of individual care providers. (e.g. Nurses have different practice style in terms of giving out/checking email, answering calls etc.)	CommCaregiver: variation in degree of communication with caregivers DirectPtCare: Practice variation in to what extent or how often the HCP has direct interaction with patients on an on-going basis (excluding first visits and chemo classes) DocumentEmailConvo: practice variation in documenting about email conversation with patients into Epic. GiveOutPersonalContact: Individual practice variance of whether the HCP gives out their personal contacts (e.g. email, phone number) to their patients

		OffHourResponse: Individual practice variance in whether or not HCPs answer patient inquiries that come in during off-hours and weekends. ProactivePtCare: Variation in how proactively HCP take care of patients TellPtAbtMyChart: Variation in whether they tell patients about MyChart; (If they do: refer to node "TalkAboutMC" for WHAT they tell patients about MyChart) TriageIndPracVar: Individual practice variance of triage nurses only TurnAroundTime: Individual practice variation in how much time the HCP takes to address patient question/concern that comes in via email, phone, or MyChart UseStationPhone: Nurses' individual practice variation of whether they communicate with patients using station phones
	HCP_PercPtInfoNeeds: HCP perceived patient info needs, seeking, sources… e.g. types of questions/concerns/requests HCPs expect or have heard in the past from patients (e.g. not knowing what the labs mean) e.g. info seeking behavior and sources patients seem to be using (e.g. google, newspaper, magazine etc.)	*(Refer to Table 6)*

	HCPPercPtProbWithCompliance: HCP PERCEPTION of patients' level and reason for (non)compliance; e.g. Because they get so much info at once, patient can't remember all information, which leads to inquiry; e.g. Patient SEEMS to be having conflicting needs that they don't listen to what the HCP tells them.	
	*HCP_PercCaregiverNeeds:*HCP perception of needs of caregivers	
	*HCPPercPtPsychological Issues:*HCP perceived or expected patient need for psychosocial support or questions/concerns pertaining to psychosocial issues; e.g. methods of coping anxiety; e.g. interpersonal/social information (such as effect on social life or leisure); e.g. some patients require more attention (TLC)	IndInfoNeedVar: HCP perception of various degree of information need in patients
		Don'tWantToDisturb: HCP perception of "patient's perception of HCP workload". i.e. patient is having some sort of information need that they want to contact HCPs but not wanting to disturb HCPs.
	PersonalExperience: HCP's personal experience (and years of experience) that affects the way they provide care	
Task	*JobAmbiguity:* Any mention of difficulty, complexity, variety, ambiguity, and sequence of a task	
	JobAutonomy: Any mention of HCP having power to control/autonomy to complete their tasks	

	JobDemands: Any mention of Job demands (e.g. workload, time pressure, cognitive load, need for attention)	
	*TriageInfoNeed:*Info need by Triage in getting their job done	
Tools/Tech	*HCP_InBasBarrierProbs:* Non-MyChart InBasket barriers and problems (mainly in terms of Triage Call process e.g. routing to/receiving patient CALLS in pools)	
	HCP_MCBarrierProbs: HCP's perceived barriers to using MyChart and Problems encountered with MyChart; Usually the responses include comparison (usability, familiarity) of traditional emailing vs. MC secure messaging	HCP_Uncertain_Wrong: Uncertainty about the tool/technology, or not having the correct information about the tool/technology. e.g. uncertain about how to use certain functions of the tool e.g. Not knowing that MyChart messages are going to the Pool, not to an individual
	HCP_MCFacilitator: How HCPs would benefit from patients' use of MyChart	
	HCP_PercPtMCBarrier: HCP perception of patient barriers to using MyChart e.g. not understanding the meaning of lab results/causing anxiety	

	HCP_PercPtMCFacilitator: HCP's perception of what patients would want to use the MyChart for or what the patients would like about MyChart. (This leads to what they emphasize when they talk about MyChart to patients = code "TalkAboutMC") e.g. Understanding info to prep for visit; proxy access for family members because patients already have a lot on plate	

Curriculum Vitae

KOKO TAKATORI

PERSONAL DETAILS

Place of Birth : Tokyo, Japan
Date of Birth : October 15th 1985
Gender : Female
Adress :7-13-6 Roppongi Minato-ku, Tokyo Japan 106-0032
Phone : +81-90-7704-0141
E-mail : kokotakatori@gmail.com

EDUCATION

Division of Health Sciences Informatics, Johns Hopkins School of Medicine: Baltimore, MD.
Candidate for M.S. in Research Health Sciences Informatics, May 2015.
Cumulative GPA 4.00/4.00.
Coursework: Human Factors in Health IT, Health Information Systems: Design to Deployment, HSI: Knowledge Engineering and Decision Support, HIT Standards and Systems Interoperability, Organizational Behavior and Management, Public Health and Biomedical Informatics, Clinical Informatics, Population Health Informatics, Fundamentals of Budgeting and Financial Management.

Tokyo Institute of Technology: Tokyo, Japan.
Non-Degree Student, March 2012.
Coursework: Advanced Topics in Intelligence Sciences, Human Interface System, Mathematical Models of Learning Mechanisms, Discrete Structures and Algorithms, Programming in C, Scheme and Java.

Wellesley College: Wellesley, MA.
B.A. in Psychology with Pre-Medicine concentration, June 2007.
Science GPA 3.65/4.00, cumulative GPA 3.54/4.00.
Coursework: Statistics, Introductory Physics, Neuroscience, Genetics, Cancer Genomics, Organic Chemistry, General Chemistry, Advanced Topics in Personality and Social Psychology, Research Methods in Abnormal Psychology, Systems of Psychotherapy.

RESEARCH

Presentation

Oncology Nursing Society 39th Annual Congress: Anaheim, CA.
Poster: "Finding Meaningful Use in Patient Portals", May 2014.
American Chemical Society 233rd National Meeting & Exposition: Chicago, IL.
Poster: "Macromolecular Release Using Thermoresponsive Anionic Hydrogels", March 2007.

Publication

Guiney, L. M., Agnello, A. D., Thomas, J. C., Takatori, K., and Flynn, N. T., *"Thermoresponsive behavior of charged* N-*isopropylacrylamide-based hydrogels containing gold nanostructures,"* **Colloid Polym Sci** (2009) 287:601–608.

GRANTS AND AWARDS

Fulbright Grant for Graduate Study, 2012 – 2013; The Amabel Boyce James Fund for Research in the Sciences, 2006; The National Dean's List, 2005 – 2006; Academic First-Year Distinction, April 2004.

PROFESSIONAL QUALIFICATIONS

Certified Fundamental Information Technology Engineer: Tokyo, Japan.
Passed the National Fundamental IT Engineer (FE) Examination, October 2010.

Certified Science Illustrator: Santa Cruz, CA.
Completed Certificate Program at UC Extension Santa Cruz in Science Illustration, June 2008.

PROFESSIONAL MEMBERSHIPS

American Medical Informatics Association (AMIA)
Healthcare Information and Management Systems Society (HIMSS)

WORK EXPERIENCE

BioDigital Systems: New York, NY.

Biomedical Visualization Intern (Summer 2008): Illustrated storyboards in digital media for 3D medical animations used in Mystery Diagnosis Season 6 (Discovery Health Channel) and an animation titled "What is Cancer?" used in Stand Up 2 Cancer campaign; created 3D still images on Autodesk Maya and Adobe Photoshop.

LANGUAGES

Japanese: Native
English: Native
Chinese: Intermediate

SKILLS AND INTERESTS

Computer Skills: Microsoft Office, NVivo, SPSS.
Web Design and Programming: HTML, CSS, Java Script, Adobe Dreamweaver, Fireworks.
Digital Illustration, Modeling, and Animation: Adobe Photoshop, Illustrator, InDesign, After Effects, Premiere, Autodesk Maya, 3ds Max.
Extracurricular: Black belt Kendoist; rock climber; guitarist.